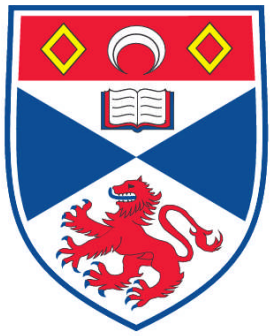
MAINTAINING PERSONHOOD AND SELF-IMAGE IN DEMENTIA: AN EXPLORATION OF COLLABORATIVE COMMUNICATION

Maggie P. Ellis

A Thesis Submitted for the Degree of PhD
at the
University of St. Andrews



2009

Maintaining Personhood and Self-Image in Dementia: An Exploration of Collaborative Communication

Maggie P. Ellis

Submitted for the Degree of Doctor of Philosophy

University of St Andrews

February, 2009

ABSTRACT

The main aim of this thesis was to explore the maintenance of personhood and self-image in dementia by way of facilitating collaborative communication between people with dementia and their caregivers/interaction partners. As such, the roles of the person with dementia and the interaction partner were examined in each study within the realms of the 'Collaborative Personhood Model'.

Findings of the first study highlighted strategies used by people with mild to severe dementia to maintain social interactions, to save-face and to maintain and project a sense of self-image in a reminiscence situation. The impact of introducing a family member as the interaction partner in a similar reminiscence-based situation using personal photographs was then explored. The findings of this study indicated that the personal nature of the photographs can create conflict between the person with dementia and her family member. Crucially, these studies illuminated the supportive role that the communication partner must adopt in order to successfully facilitate people with dementia to maximise their retained communication skills. Communication and sense of self was then examined in an individual with very severe dementia with some retained speech. The findings of this study illuminated the potential of imitation in communicating with people at this stage of the illness. These findings were then built upon by exploring the use of Intensive Interaction (II) in a person with very advanced dementia with no retained speech. Findings of this study indicated retained awareness of self and functional communication skills at very late stages of dementia. Finally, this study was expanded using a modified version of II (Adaptive Interaction) in a small group of individuals with very severe dementia with

very little or no retained speech. These findings indicated an unprecedented desire and ability to communicate in people with such severe dementia.

Taken as a whole, these studies highlighted the adaptive and collaborative role that the interaction partner must adopt in order to facilitate the maintenance of personhood and self-image in people with dementia. More specifically, the interaction partner must adjust to the communicative repertoire that is maintained at each stage of dementia and in each individual. The 'Collaborative Personhood Model' represents an attempt to explain how this might be achieved.

I, Maggie P. Ellis, hereby certify that this thesis, which is approximately 50,000 words in length, has been written by me, that it is the record of work carried out by me and that it has not been submitted in any previous application for a higher degree.

I was admitted as a research student in May 2002 and as a candidate for the degree of Ph.D. in Psychology; the higher study for which this is a record was carried out in the University of St Andrews between 2002 and 2009.

Date 21.10.09 signature of candidate

I hereby certify that the candidate has fulfilled the conditions of the Resolution and Regulations appropriate for the degree of Ph.D. in the University of St Andrews and that the candidate is qualified to submit this thesis in application for that degree.

Date 21.10.09 signature of supervisor

In submitting this thesis to the University of St Andrews we understand that we are giving permission for it to be made available for use in accordance with the regulations of the University Library for the time being in force, subject to any copyright vested in the work not being affected thereby. We also understand that the title and the abstract will be published, and that a copy of the work may be made and supplied to any bona fide library or research worker, that my thesis will be electronically accessible for personal or research use unless exempt by award of an embargo as requested below, and that the library has the right to migrate my thesis into new electronic forms as required to ensure continued access to the thesis. We have obtained any third-party copyright permissions that may be required in order to allow such access and migration, or have requested the appropriate embargo below.

The following is an agreed request by candidate and supervisor regarding the electronic publication of this thesis:

Access to Printed copy and electronic publication of thesis through the University of St Andrews.

Date 21.10.09 signature of candidate

signature of supervisor

ACKNOWLEDGEMENTS

First and foremost, I would like to give special thanks to my supervisor, colleague and friend Dr Arlene Astell for her guidance and support over the years. You are an outstanding teacher and I am extremely proud to have been one of your postgraduate students. I cannot thank you enough and sincerely hope to continue working with you in the future.

Special thanks also go to Allison Lee who as one of my oldest (and most sensible) friends first sparked my interest in dementia. I would not have reached this milestone without you. You have created a monster!

I wish to thank all who took part in this research – the professional and family caregivers, managers and in particular, the individuals with dementia who continue to inspire me. Special thanks are extended to Mrs Edie Adams and her daughter Liz Evans for their crucial roles in this work.

My colleagues from the CIRCA/LIM Projects team deserve a special mention of gratitude – Dr Norman Alm, Dr Richard Dye, Mr Gary Gowans, Mr Jim Campbell and Mr Phil Vaughan. I would also like to extend my appreciation to my second supervisor, Professor Steve Reicher for his enthusiasm and support.

My thanks are also extended to all students who have helped me with data collection and reliability, namely, Elaine Cameron, Jason Yuan, Celine Eggen and Sarah Birch. I would also like to give special thanks to Dr Michelle 'Shell-Doll' O'Neill and Dr Paul Escalante-Mead for their unfailing friendship, advice and optimism. Also, (soon to be Dr) Phil Riley deserves a special thank you for her participation in the 3-legged race towards the finish line. I promise to return the favour when the time comes. You're a star!

Hugs go out to my family and friends and to my dogs (past and present) for putting up with me, encouraging me and making me laugh (cheers Carol ☺). Finally, I would like to dedicate this thesis to my dad, Harry Ellis who has waited a long time for this moment and whose constant reminders to that end have helped to maintain my focus. Thanks dad!

CONTENTS

CHAPTER THREE: RETAINED COMMUNICATION SKILLS AND SELF-AWARENESS IN DEMENTIA: FACILITATIVE STRATEGIES

CHAPTER FOUR: STUDY 1 - THE IMPACT OF DEMENTIA PROGRESSION ON PERSONHOOD AND THE CONSTRUCTION OF SELF

CHAPTER SEVEN: STUDY 4 - INTENSIVE INTERACTION IN VERY SEVERE DEMENTIA: A CASE STUDY

CHAPTER EIGHT: STUDY 5 - ADAPTIVE INTERACTION IN VERY SEVERE DEMENTIA

CHAPTER NINE: GENERAL DISCUSSION

TABLES

CHAPTER TWO

CHAPTER THREE

CHAPTER FOUR

CHAPTER SEVEN

CHAPTER EIGHT

FIGURES

CHAPTER ONE

CHAPTER TWO

CHAPTER FIVE

CHAPTER SIX

CHAPTER SEVEN

CHAPTER EIGHT

CHAPTER 1

INTRODUCTION

1.1. The Social Nature of Humans and the Significance of Communication

Humans are characteristically social beings and as such, strive to communicate as soon as they enter the world (Meltzoff & Moore, 1983; Valenza et al, 1996). Through communication with others we share information about ourselves and each other which is ultimately essential to our survival (MacDonald & Leary, 2005). For example, a newborn infant cries when hungry and his mother quickly learns to respond to this cue by providing him with food. Without this type of basic communication the infant's chances of survival would greatly reduce.

Human communication fulfils a number of other equally important functions essential to human survival. In evolutionary terms, social animals that were well integrated into their family groups and formed strong bonds with other animals were more likely to survive than those that did not seek out the company of others. In other words 'for social animals, being socially excluded was often equivalent to death' (MacDonald & Leary, 2005, p.203). Although perhaps less imminently life-threatening in today's world, the effect of social exclusion remains noteworthy. Indeed the impact of social rejection is regarded to be *so* significant that it has even been related to physical pain via mediation by the same physiological system (ibid.)

1.2. The Fundamentals of Human Communication

Although communicative bids in infants are undoubtedly primitive, they are nevertheless evident from the moment of birth often in the form of imitative behaviours. Babies are apparently born equipped to respond to human faces (Valenza, Simion, Macchi-Cassia & Umilta, 1996) and can mimic simple facial

activities, such as sticking out the tongue (Meltzoff & Moore, 1983). Such imitative behaviours suggest that humans have an innate predisposition to communicate and interact with others. Parents of newborns typically repeat and reinforce the facial expressions, sounds and movements made by their infants. This imitation forms the basis of their early interactions and provides the foundation for future communication. In parent-infant interactions this reciprocal behaviour arises quite naturally and is both spontaneous and unselfconscious (Tomasello, 1992).

Infants' communication skills develop as a result of engaging with their parents in this 'protoconversation' and continue to improve with their further support and encouragement (Papousek, 1995). Indeed, according to Vygotskian theory *all* cognitive skills, including language and self-awareness originate in social interactions with more skilled individuals (Vygotsky, 1978; Haden, 1998). With regard to communication, parents facilitate the use of language and self-awareness by interacting with their babies 'as if' their early communicative bids were meaningful to them (Newson, 1978). Known as 'scaffolding', this behaviour allows the infant to communicate with his parent in a way that although void of recognisable structure and linguistic content, is nevertheless meaningful to both of them (Vygotsky, 1978). Consequently, infants become increasingly aware of the effects of their behaviour on others and of their status as increasingly effective communicators.

1.3. Personhood, the Self and Intersubjectivity

The willingness to communicate by its very nature suggests a strong sense of self and other (Trevarthen & Aitken, 2001). The attribution of 'personhood' to the infant (or to any other individual) is 'co-created' in much the same way as the

development of his cognitive and communication skills: that is, in co-operation with another individual (Vygotsky, 1978). The attribution of ‘personhood’ to an individual represents an affirmation of his established status as a person in every sense of the word. However, this standing cannot be recognised by the individual independently. In other words, personhood is socially constructed and is maintained by relationships that encourage effective and supportive communication (Kitwood & Bredin, 1992).

Personhood is intrinsically linked to the concept of ‘intersubjectivity’ which refers to the innate human ability to comprehend and appreciate each other (Rommetveit, 1974). Rommetveit (1974) argued that even the simplest communicative act rests upon the participants' mutual commitment to "…a temporarily shared social world" (Rommetveit, 1974, p. 29). In other words, intersubjectivity is recognised as a social construct that is neither implicit in the knowledge participants bring to the situation, nor is it explicitly coded in their language. Rather, it must be constructed between communicators anew for each interaction. Trevarthen (2004) posited that in order for us to understand how this is possible, we must regard all human action as communicative.

In order to co-create personhood, two individuals must first achieve intersubjectivity which is accomplished through interpersonal communication. From this point of view we can more easily understand the development of communication and how infants and parents first begin to interact. In order to discuss communication as both a collaborative act and one that is vital to human life, a framework must first be introduced that encompasses these concepts and considers them as interdependent. Models of interpersonal communication are many and varied; so much so that the discussion of their range is out with the scope of this

thesis. However, two main theory strands in this area will be briefly introduced followed by the reasons why communication will be explained within the reaches of Social Constructionist Theory in this thesis (Coulter, 1981; Harré, 1983, 1991). Figure 1.1. depicts the relationship between intersubjectivity and personhood.

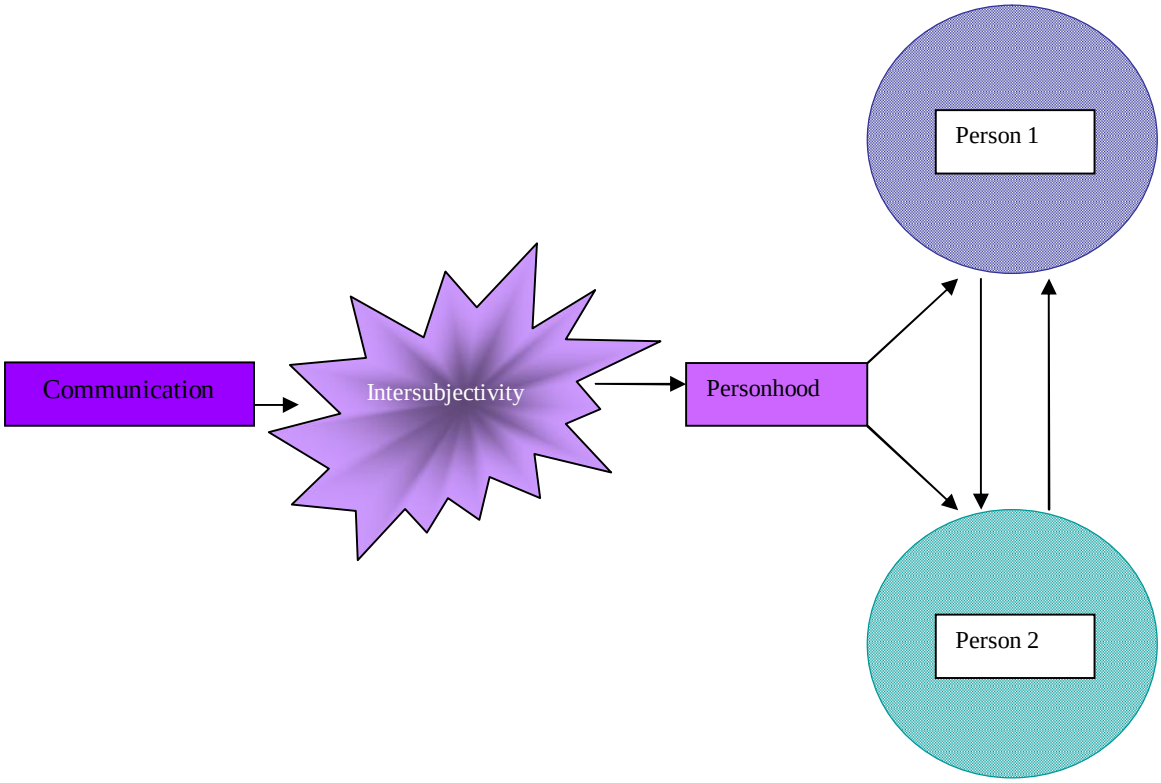


Figure 1.1. The relationship between intersubjectivity and personhood.

1.4. Monologic Models of Interpersonal Communication

Monologic models of communication refer to the types of interactions within which communicators are far more interested in themselves than in the relationship between each other (Buber, 1937). Coined by Buber (1937) as the 'I-It' relationship, monologic communication involves the passing and deciphering of verbal messages between interaction partners resulting in an exchange of information. Where these models differ is how communicative bids are received. For example, in the 'encoding and decoding' model (Wiener, Devoe, Rubinow & Geller, 1972; cited in

Krauss, 2005) the listener decodes the signals put forward by the speaker in order to decipher his underlying ideas. The 'communicative intentions' (Grice, 1969; cited in Krauss, 2005) model differs from this only in that the job of the listener is to identify the communicative intention of the communicator. Finally, the 'perspective-taking' model (Rommetveit, 1974; cited in Krauss, 2005) involves both the listener and communicator attempting to take each other's perspectives into account. This model comes close to addressing the collaborative nature of human interaction but regards perspective-taking as involving separate efforts from both parties.

The above models of communication view the communicator and listener as 'autonomous information processors' in a well-defined and organised communicative setting. Perhaps most adherent to this line of thought is the 'encoding and decoding' model which regards both partners simply as input and output sources with no regard for the perspective of each other. Although the 'communication intentions' and 'perspective-taking' models attempt to take the partner's position into consideration in some way they miss out one vital component of communication. Human social exchange is a 'joint accomplishment' by partners who have a shared communicative goal in mind. As such, the meanings of the messages in the conversation are dependent upon the social situation within which they are exchanged. Subsequently, the individual inputs of the communicator and listener do not hold the same meaning out with that particular social exchange (Krauss, 2005).

1.5. Dialogic Models of Communication

As in the monologic models, the dialogic model of communication considers speech as the main method of human interaction but it differs significantly in how it regards the goal of the communication. Born out of Buber's (1937) theory of the 'I-

Thou' relationship, according to the dialogic model, the goal of the interaction is not simply to exchange information (as in the monologic models); rather the main aim is to achieve 'intersubjectivity' or mutual understanding (Buber, 1937; Krauss, 2005). On a more abstract level dialogic models serve more as an approach or attitude towards rather than a method of communication (Thomlison, 1982). In dialogic models of interaction, both communication partners show a genuine regard for and seek to understand the experiences of each other. Buber (1937) posited that a true connection with another person, or 'I-Thou' relationship can be derived only from 'the between': the part of human life that links self and others; that holds all co-created human entities such as the self, communication and language (Anderson & Ross, 1994; cited in Thomlison, 1982). In essence, 'the between' represents the unique shared meaning and relationship that are co- created by both partners in the interaction (Thomlison, 1982). Figure 1.2. depicts Buber's (1937) dialogic model of interpersonal communication showing 'the between'.

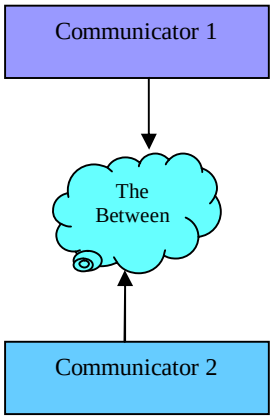


Figure 1.2. Buber's dialogic model of interpersonal communication showing 'the between'.

1.6. The Collaborative Model (Clark & Brennan, 1991)

One example of a dialogic model is Clark & Brennan's (1991) collaborative theory. In an effort to explain the aim and outcome of concerted effort in human interaction, Clark & Brennan posited that communication amounts to much more than the exchange of spoken messages between conversational partners. Rather, the researchers regarded communication as a collaborative effort in that both partners seek to work with and understand each other. For example, should a misunderstanding arise in a conversation both partners will make an effort to resolve it. By engaging in this process, both partners work to expend the 'least collaborative effort' (Clark & Wilkes-Gibb, 1986). In other words, one partner might make an extra effort to minimise the collective effort made by both (Clark & Brennan, 1995). It is this form of joint endeavour that represents the basis of facilitative interaction with individuals who experience communication difficulties. For example, infants who have yet to develop speech, individuals who have never learned to talk perhaps as a result of severe autism or people who have lost the ability to speak as a result of a dementing illness *all* fall into this category. As such, the advantaged or more experienced communication partner must make an extra effort to allow both partners to expend the least collaborative effort. However, in order for this process to begin the advantaged communicator must first regard all of the disadvantaged communicator's behaviours as intentionally communicative. Figure 1.3. depicts a representation of Clark & Brennan's (1991) Collaborative Model.

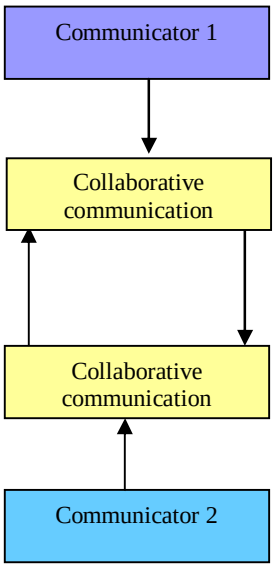


Figure 1.3. Representation of Clark & Brennan's (1991) Collaborative Model.

1.7. Disadvantaged Communicators

The process by which healthy infants enter into the social world has been previously outlined in this chapter (1.2). We may view the infant as a disadvantaged communicator in that he attempts to communicate in an environment that is dominated by speech – a form of communication he is yet to comprehend and use. However, as facilitative 'protoconversation' increases between the infant and his parents, he slowly begins to develop an understanding of and an ability to use language. As such, the healthy infant remains a disadvantaged communicator for a relatively short period of his life and is quickly accepted as a social agent.

Individuals with severe autism very often experience profound communication difficulties from birth. As such, the communication skills of autistic infants and children tend to develop 'atypically' and often these individuals never become able to use recognisable speech at all. Getting to grips with the social world is not an easy task for autistic people as the supportive communication that develops

between healthy infants and their parents is typically impaired owing both to cognitive difficulties experienced by the person with autism and the inability of his parents to communicate in a way that is meaningful to him. Consequently, the individual with severe autism is accepted as an 'atypical' social agent. Indeed, it has previously been suggested that this drive to communicate with others is lacking altogether in ASD (Hobson, 1993). Nadel's work, however, suggests that not only can people with ASD participate in social situations they also have awareness of others as separate individuals and a demonstrable urge to interact and communicate. This latter point was illuminated through the 'Still Face' paradigm, a controversial manipulation of the social situation (Nadel, Croue, Mattlinger, Canet, Lecuyer & Martini, 2000). This work will be further discussed in Chapter 6.

Intensive Interaction (II) is another example of a facilitative communication method that is based on the fundamentals of human interaction. This approach focuses on people with profound learning disabilities who have severe communication impairments. Such individuals may never have experienced meaningful communication with another person and as such, this approach affords them entry to a social world from which they have been previously been excluded. The focus of II is on regular non-verbal and subvocal exchanges with little or no involvement of speech between two people, one of whom experiences difficulty communicating with others. The quality of the interaction is all-important in II and there is no emphasis on task performance or achieving specific outcomes (Nind, 1999). The key to II is that the behaviour of the nonverbal participant is viewed as intentionally communicative. This approach will be further explored in Chapter 7.

People who have lost their communication skills as the result of a dementing illness experience a very different course from communicatively typical and atypical

individuals in that they attempt to maintain their grip on the social world as opposed to enter into it. Dementia is an illness that involves progressive global decline in all aspects of functioning not least of which is communication and participation in social interactions. The majority of people who develop dementia are over 65 and as the illness develops they experience progressive social isolation (Abad, 2002). This occurs not only as a result of their increasingly impaired communication skills but also arises as a consequence of those around them making fewer attempts to communicate (Kitwood, 1997). By the time dementia reaches the later stages, people with a diagnosis may appear to be completely unreachable, which results in those who care for them no longer attempting to engage them in interactions. As such, individuals with severe dementia are increasingly excluded from the social world and are therefore negated as social agents. Consequently, functional approaches to communication for individuals at this severe stage are few and far between.

When examining the experiences of these communicatively disadvantaged populations within the collaborative model it becomes clear that communication breakdown occurs or is likely to occur during collaborative communication. It would appear that the role of the advantaged partner is crucial to the development or performance of the disadvantaged person. In other words, communication will fail if the advantaged partner does not facilitate the interaction by working to expend the 'least collaborative effort' (Clark & Wilkes-Gibb, 1986). It becomes the task of the interaction partner to "use (his) creativity to establish a new channel of communication" (Kitwood, 1997, p.3.). Communication in individuals with dementia is different to both 'typical' and 'atypical' groups in that their skills and needs are constantly changing with each stage of the illness. Also, unlike these other groups, the majority of people with dementia were previously able to communicate

expertly and functioned in the human social world without any major difficulties. Figure 1.4. depicts the trajectory of communication skills in disadvantaged communicators.

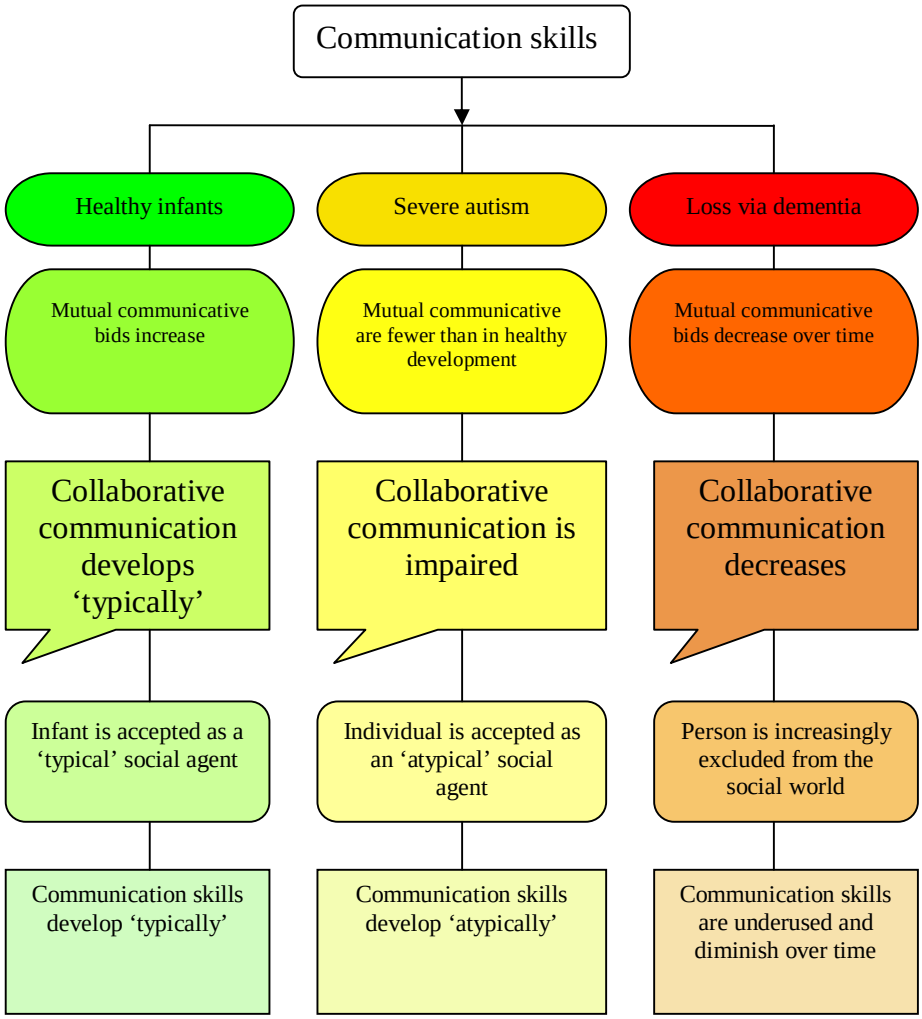


Figure 1.4. The trajectory of communication skills in disadvantaged communicators.

1.8. Focus on Dementia

Improving interpersonal communication between people with dementia and their caregivers could improve both the job satisfaction of care staff and the quality of life of people with dementia (Woods, 1999). Facilitating the co-creation of personhood and maintenance of self-image via collaborative communication with

people with dementia is crucial to this. The challenge is how to facilitate communication with people with dementia at different stages of the illness. However, a combination of the retained communicative behaviours of the person with dementia and facilitative interaction by the caregiver could form the basis of interventions designed specifically for individuals at each stage of dementia. In short, collaborative communication represents the crucial area that may well have the potential to enhance the lives of people with dementia those who care for them.

1.9. Thesis Outline

Dementia has a progressively degenerative impact on all areas of cognition. Of particular significance to those with a diagnosis and their caregivers is the effect it has on communication. The impact on both parties advances at each stage of the illness as communication and oftentimes relationships slowly deteriorate. This thesis explores 3 main strands of the communication process between people with dementia and their caregivers. Firstly, the communication changes that occur as the illness progresses and those skills are maintained will be identified. Secondly, the relationship between retained communication skills and the self will be explored. Finally, the role of the advantaged interaction partner in facilitating and maintaining communication and self –image with people with dementia will be examined. The crucial role of the advantaged interaction partner will be regarded as the main force in facilitating and maintaining communication and selfhood with people with dementia. As such, this thesis explores a range of collaborative methods designed to facilitate communication and personhood and self-image between people with a diagnosis and their caregivers at different points in the illness. Tying the thesis together is the view of communication as a socially collaborative process that occurs

between communication partners. In other words, human interaction will be regarded as something that is constructed between people and as such will not be viewed solely in terms of individual communicative contributions.

Chapter 2 introduces dementia and the impact of the illness on interpersonal communication, relationships and self. Chapter 3 then goes on to discuss the communication skills and awareness of self that are retained at different stages of dementia and how facilitation strategies maximise these. As such, this chapter identifies and discusses several communication augmentation techniques that have been researched in recent years. This chapter ends by summing up the areas of communication and self in dementia that are yet to be addressed by these techniques and proposes a model of preservation of self via collaborative communication ('Collaborative Personhood Model') that will be used throughout the thesis.

Chapter 4 represents the first empirical chapter of the thesis and contains a major study on retained communication, i.e. strategies used by people with mild to severe dementia to maintain social interactions, to save-face and to maintain and project self-image in social situations. This study uses a reminiscence situation as a vehicle to allow people with dementia to hold a conversation in response to a set of photographs representing a range of annual events. I (hereafter referred to as the investigator) served as the healthy interaction partner in this study. The findings of this study indicate a desire to communicate and maintained self-awareness even at the later stages of the illness.

Chapter 5 then goes on to further explore the role of the interaction partner in a similar reminiscence-based situation, this time using personal photographs with a family member serving as the interaction partner. Firstly a reminiscence session between the investigator and the family member was conducted in order to glean

information about the contents of the images. Then reminiscence sessions were conducted between the participants with dementia and the investigator and the responses of people with dementia and their family members were analysed. Finally, the same process was repeated with people with dementia encompassing their family member as the interaction partner. The findings of this study indicated that the personal nature of the photographs can create tension between people with dementia and their family members. For example, the family member may become upset should the person with dementia fail to recognise a close family member in one of the images. The findings of the first two studies indicated a wide range of retained communication skills, self knowledge and self-awareness at all stages of the illness. Crucially, these studies illuminated the supportive role that the communication partner must adopt in order to successfully facilitate people with dementia to maximise their retained communication skills.

Chapter 6 then goes on to explore communication and sense of self in an individual with very severe dementia with some retained speech. This chapter employs a range of imitation based activities and illustrates how this strategy can be utilised to illustrate a retained desire to communicate and project self in a person with very severe dementia. Chapter 7 expands on these findings by exploring the use of Intensive Interaction in a single case study. This study is expanded in Chapter 8 using similar communication technique (Adaptive Interaction) in a small group of individuals with very severe dementia with very little or no retained speech. The findings of Chapters 7 and 8 indicate an unprecedented desire and ability to communicate in people with such severe dementia. As such, the studies in this chapter form the basis of a new and exciting approach to communicating with and facilitating the maintenance of self in people very severe dementia.

Chapter 9 serves as a general discussion of the studies in the thesis in respect to their contribution to our understanding of the retained communication skills at all stages of dementia and how they relate to self; and of the role of the healthy communication partner in facilitating these.

CHAPTER 2

THE IMPACT OF DEMENTIA ON THE SELF, INTERPERSONAL COMMUNICATION AND RELATIONSHIPS

2.1. Communicating Self

As discussed in Chapter 1, the urge to communicate by its very nature suggests a robust sense of self and other (Trevarthen & Aitken, 2001). The concept and significance of self to humans has historically been at the heart of much complex philosophical debate, which is beyond the scope of this thesis. The focus here is on the concept of self and its significance to humans within an interactional framework, informed by Social Constructionist Theory (Coulter, 1981; Harré, 1983, 1991)

Social Constructionist Theory (Coulter, 1981; Harré, 1983, 1991) explains the formation and maintenance of self in terms of the interactions that take place between individuals. Through our social interactions we understand who we are as individuals, how others view us and our views of others develop. Consequently, a person's self-image may be very different to how other individuals regard him. In accordance with the model of communication employed in this thesis (Clark & Brennan, 1991) Social Constructionist Theory asserts that there are 3 discernable aspects of 'selfhood', known as 'self 1', 'self 2' and 'self 3' (Sabat, 2000). 'Self 1' represents the "self of personal identity" (Sabat, 2000, p.276), which is thought to be most often expressed in linguistic terms via 'first person indexical pronouns' such as 'I', 'me', or 'my' or by adjectives such as 'mine' or 'myself'. These indexical terms allow the speaker to illustrate that he is aware of his status as an individual who is separate to other people and objects and who has her own perspective on the world. 'Self 2' represents the "self of mental and physical attributes" (Sabat, 2000, p.290),

e.g. being a postgraduate student and being an atheist or being 6 feet tall and having good eyesight. Some of the attributes of 'self 2' may change over the course of time (e.g. having good eyesight) and some may remain constant (e.g. being 6 feet tall). Other attributes of 'self 2' may be longstanding (e.g. being an atheist) and others may be relatively recent (e.g. being a postgraduate student). Awareness of 'self 2' is also demonstrated through statements of an individual's mental constructs such as their beliefs, emotions and desires. 'Self 3' represents the "socially presented selves or personae" (Sabat, 2000, p.294), i.e. the different versions of self that are constructed in various social situations. For example, an individual might have multiple personae such as those of a loving wife, a supportive mother, a dutiful child, an enthusiastic teacher and a loyal friend. The crucial element of these 'self 3' personae is that they are constructed socially, i.e. in collaboration with others. In other words, if her pupils did not consider her to be enthusiastic, the persona of 'enthusiastic teacher' in the previous example would be negated (Sabat & Harré, 1992; Small, Geldart, Gutman & Clarke Scott, 1998;). Thereby, without some form of collaborative communication, the construction of 'self 3' personae would not have occurred in the first place, let alone be maintained. Taken as a whole, the three 'selves' can be conceptualised as the individual's self-image, i.e. in verbal terms, 'self 1' can be thought of as "I exist"; 'self 2' could be verbalised as "This is what I am like" and 'self 3' may be verbally represented by "These are my different roles in life".

The drive to communicate and the development of self-awareness represent early-appearing human attributes that are crucial to functioning in the social world (Meltzoff & Moore, 1983; Valenza, Simion, Macchi-Cassia & Umilta, 1996). By engaging in reminiscence with their peers and parents, children develop a sense of

self as soon as they can talk (Haden, 1998). Early verbal interactions with parents involve the structuring of past events and conversations which play a vital role in facilitating the development of verbal communication, relationships and the co-creation of self (ibid.). As we develop, the reminiscence process allows us to explore and project our identities by sharing the life experiences that have played a part in making us who we are (Parker, 1995). Indeed, reminiscence is one of the most prevalent methods of communicating information about the self both in early development and throughout the lifespan (Merriam & Cross, 1982; Romanuik & Romanuik, 1983; De Vries, Blando & Walker, 1995; Webster, 1995).

The awareness of self is largely communicated via speech, with verbal face-saving strategies signifying further development of self-consciousness in response to our view of how others see us (Goffman, 1955; 1959). Face-saving strategies are apparent in conversation by our attempts to mask self-consciousness and embarrassment. Goffman (1955, 1959) theorised that face-saving strategies are motivated by individuals' desire to appear capable to others and to avoid becoming publicly embarrassed. Therefore, 'face' is highly dependent on how we view our own self-image in the eyes of those with whom we interact (Brown, 1970). People who become embarrassed in public will go to great lengths to conceal the source of their discomfort (Goffman, 1959). This is costly to the individual and indicates that face-saving is intrinsically linked to feelings of embarrassment and shame (Brown, 1970).

The willingness to communicate and the use of face-saving strategies therefore illuminate a strong sense of self and self-image. By engaging in these activities we show an awareness of self both as individuals and of others' expectations of how we should behave. The concept of self therefore is one that is

both created *by* and crucial *to* human interaction. The significance of this for people with dementia is explored further at the end of this chapter (Section 2.6.).

2.2. Defining and Measuring Dementia

Increasing longevity in the Western world is bringing increasing numbers of people with disorders of old age. Prime among these is dementia, a disorder attributable to a number of different causes, most notably Alzheimer's disease (AD), which is thought to account for up to 80% of cases (Terry, 2006). Although AD is the most common cause of dementia it can only be positively diagnosed at autopsy due to the nature of its associated brain pathology. However, a clinical diagnosis of probable Alzheimer's disease (AD) can be agreed if symptoms fulfil NINCDS-ADRDA diagnostic criteria (McKhann et al, 1984). Indicators of AD include deficits in functional abilities or 'activities of daily living'/ADL's, (i.e. washing, cooking, shopping, etc.) episodic memory/EM, (i.e. the memory of recent autobiographical events) and working memory/WM, (i.e. the temporary storage and manipulation of information), combined with relatively spared long-term memory/LTM (i.e. the permanent storage and manipulation of information). The diagnosis of AD is also supported by progressive deficits in language (aphasia), motor skills (apraxia), and perception (agnosia). Memory is usually affected early in the course of the illness, although *all* aspects of cognition, including speech, problem solving, perception, decision-making and functional abilities are disrupted over time (Raia, 1999). The symptoms of dementia impede people's ability to participate in most daily activities, not least of which is communication and participation in social interactions (Ellis & Astell, 2008).

The participants in this thesis, with one exception, had been given a diagnosis of either probable Alzheimer's disease (AD) or 'dementia' in the absence of any other identified cause or co-morbid illnesses (e.g. Parkinson's disease). This afforded the opportunity to work with a group of individuals with the same or similar diagnoses and who therefore had relatively comparable symptoms. Although Alzheimer's disease affects individuals in different ways, selecting the participants according to these criteria engendered a level of consistency throughout the research. As such, the terms Alzheimer's disease (AD) and 'dementia' will be used interchangeably throughout this thesis to refer to the same condition.

The most commonly used and researched measure of dementia is the Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975). The MMSE measures cognitive function in the following domains: orientation to time, orientation to place, language, attention, visual construction, registration and recall (ibid). Patients are scored out of 30 over the 7 domains and the severity/stage of dementia is defined in the following way: mild – (MMSE score greater than or equal to 20); moderate – (MMSE score between 19 and 10); severe – (MMSE score < or equal to 9). A full copy of the MMSE can be found in Appendix II. In behavioural terms, the MMSE is known to correlate negatively with activities of daily living (Galasko, 1998 – see Figure 2.1).

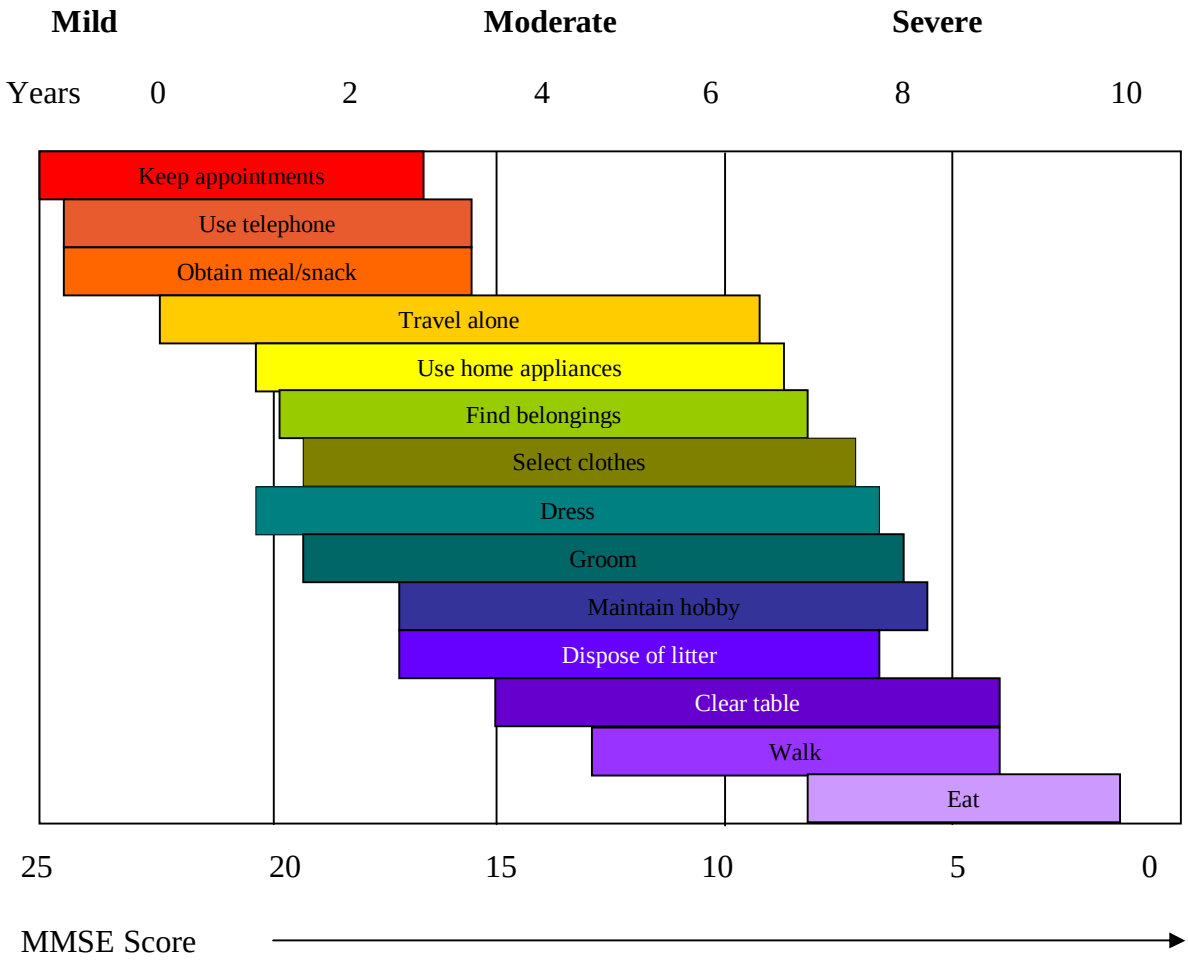


Figure 2.1. The natural progression of AD showing the 3 MMSE stages in relation to function in activities of daily living (adapted from Galasko, 1998).

The MMSE is widely used both in assessment and research as it can quickly identify any prominent cognitive difficulties. However, many people reach a point where their dementia is so severe they cannot be assessed using the MMSE and are classified as 'severe' or 'very severe' dementia. In addition, the mild, moderate and severe stage criteria are very broad and symptoms overlap a great deal across the categories (Kitwood, 1997). Indeed, Bell & McGregor (1995) are amongst numerous authors who argue against stage theories of dementia. Essentially, they assert that a

stage theory is too simplistic to illustrate the many and complex ways that dementia affects those with the illness. The course of dementia is different for each individual and is dependent on a combination of several different factors. For example, the type of dementia, the presence of other illnesses, the level of support and care given, the age of onset, etc. all have a role to play in the trajectory of the illness. Even in the face of such disparity it is nevertheless useful to employ a set of criteria within which the severity and types of symptoms of dementia can be staged, albeit in a general way. Therefore, the MMSE is used as a measure throughout this thesis in order to provide the reader with a general indication of dementia severity.

2.3. The Impact of Dementia on Communication

Due to progressive deterioration of working memory (WM), people with AD experience increasing difficulties with communication. Specifically, this arises as WM deterioration impairs their ability to keep hold of and use information during a conversation. Consequently, the speech of people with AD may often seem repetitive and difficult to follow. This repetition may leave caregivers of people with AD feeling frustrated or hurt as they interpret it as the person with a diagnosis ignoring them or being deliberately difficult, and may contribute to subsequent strain and tension in their relationships (Almberg, Grafstrom, & Winblad, 1997).

In an informative review of both anecdotal and empirical accounts of the conversational difficulties of people with AD, Orange & Purves (1996) summarised the findings of key studies on the impact of dementia on communication (Table 2.1). These findings highlight the focus of most previous studies on identifying deficits in people with a diagnosis.

Table 2.1. Summary of selected studies of conversation in individuals with Alzheimer's disease (*cited in Orange & Purves, 1996; **cited in March, Pattison & Wales, 2009; ***cited in Orange & Purves, 1996 and March, Pattison & Wales, 2009.

Studies	**Conversational Features**
*Alpert et al., 1990	Egocentric conversation
*Bayles, 1984	Less adherence to conventions of conversation
*Bayles & Kaszniak, 1987	Do not ask for clarification
*Lebrun et al., 1987	Fluctuating relevance and accuracy of responses to questions
*Stevens, 1985	Topic maintenance and turn-taking problems
*Sandman et al, 1988	Insensitive to others in conversation
	Failing to repair misunderstandings
	Shrinking vocabulary
*Fuld et al., 1982	Intrusions of words and themes, unable to engage in extended discourse
*Nicholas et al., 1985	Partners unable to follow verbal output
*Richardson & Marquardt, 1985	Disrupted reference
*Ripich & Terrell, 1988	Inappropriate utterances to context, ideational verbal perseverations
*Hutchinson & Jensen, 1980	Abrupt topic shifting

*Irigaray, 1967 *Garcia & Joanette, 1997 *Mentis et al., 1995 *Sandman et al., 1988 *St. Pierre, Wilk & Orange, 1995	Topic change and introduction problems
*Santo Pietro et al., 1990	Content of utterances disordered
	Group termed 'Empty Speech' use indefinite terms primarily
	Group termed 'Violators of Conversation Conventions' use of brief affirmations primarily
*Ripich & Terrell, 1988	Structural cohesive devices used more effectively than semantic cohesive devices
***Ripich et al., 1991	Absence of nominal reference units contributes to disrupted coherence
***Garcia & Joanete, 1994	Propositions and coherence devices used in manner similar to normal elders
	Twice the disrupted cohesion in individuals with AD versus normals
**Watson, Chenery & Carter, 1999	Discontinuity in semantic cohesion (absent referents and missing units of information)
	More words and shorter conversational turns
	Independent judgements describe output as incoherent

*Hamilton, 1994a; 1994b *Penn, Sonnenberg & Schnaier, 1988 *Ripich et al., 1991 *Sabat, 1991 *Orange et al., 1995 *Orange & Mathew, 1994	Increase percentage of discourse errors and 'Wh' questions by moderate stage
**Chapman, Highley & Thompson, 1998	Difficulties in expressing communicative intentions
	Difficulties maintaining language and information balance
	Problems with drawing inferences
**Bayles et al, 1989	Fewer narrative themes than controls
**Blanken et al, 1987 **Bucks et al, 2000 **Giles et al, 1996 ***Nicholas et al, 1985	Fewer information units and nouns
**Almor et al, 1999	More pronouns with no antecedents or referents than controls
**Hier et al, 1985	More deictic words than controls
**Almor et al, 1999	More demonstratives than controls
***Hier et al, 1985	More pronouns than controls
***Nicholas et al, 1985	More referential errors than controls

***Ulatowska, 1988	
Vuorinen, Laine & Rinne, 2000	Fewer semantic units produced than controls

The literature on the production of spontaneous speech in AD is dominated by reports of progressive difficulties in communicative function such as word-finding and verbal fluency, increased paraphasic errors and circumlocutory speech (Singh, Bucks, & Cuerden, 2001). Other qualitative deficits such as impaired ability to keep track of a conversation and a reduction in meaningful speech have also been reported (Alberoni, Baddeley, Della Salla, Logie & Spinnler, 1992; Richardson & Marquardt, 1985; Tomoeda & Bayles, 1993). Quantitative changes have also been noted in the spontaneous conversational output of people with AD. Bucks, Singh, Cuerden & Wilcock, (2000) reported that in comparison to healthy controls, people with AD produced fewer nouns, had higher rates of adjectives, verbs and pronouns and produced less lexically rich speech. The authors concluded that these speech production measures could effectively discriminate between AD patients and healthy controls (Bucks, et al. 2000).

As the disease progresses, the person with AD will take shorter conversational turns with longer pauses between these turns (Alpert, Rosen, Welkowitz, & Lieberman, 1990). People with dementia in the moderate stage are also known to have higher proportions of 'discourse impairing' features such as disruptive topic changes and empty phrases than healthy age-matched controls (Dijkstra, Bourgeois, Allen & Burgio, 2004). Subsequently, these production difficulties have an adverse effect on the flow of conversation, making it difficult for a conversational partner to know when to speak. In addition, caregivers of people

with AD report a relationship between disease severity and the emergence of reading difficulties, an increase in disjointed discourse, discussion of topics that caregivers judge 'meaningless' and an inability to identify humour (Bayles & Tomoeda, 1991).

Anecdotal accounts suggest that people with dementia engage in egocentric conversation, show little adherence to the rules of normal conversation (Bayles, 1984), neither ask questions of their conversation partner nor talk about their own utterances, display a waning vocabulary and frequent digressions, use few ideational statements and provide lengthy and ambiguous responses to questions (Alpert, Rosen, Welkowitz & Lieberman, 1990; Bayles & Kaszniak, 1987; Lebrun, Devereux & Rousseau, 1987; Stevens, 1987). Further evidence suggests that people with dementia regularly show difficulty in maintaining conversation topics, turn-taking and repairing misunderstandings, tending to engage in repetitious, circumlocutory and 'off-target' speech that strays from topic to topic (Gold, Andres & Arbuckle, 1994). This often results in interactions that are both demanding and dissatisfying, particularly to family members who may feel as though their contributions are being marginalised (Astell, Ellis, Bernardi, Bowes, Tunnard & Webb, 2005). Repetitious conversation in dementia is also a main contributor to negative attitudes towards the cognitive capabilities of those with a diagnosis (but see section 3.2.).

It has also been noted that people with dementia can display insensitivity to others in conversation and are prone to either talking too much or too little (Bayles & Kaszniak, 1987; cited in Orange & Purves, 1996). Orange & Purves (1996) also quote several studies examining comprehensibility in the conversation of people with dementia. Comprehensibility is thought to be dependent on several characteristics of the speech of people with dementia, namely, perseverations (ibid.), the… "use of indefinite, deictic terms, disrupted reference, topic digressions with

abrupt topic shifts and inappropriate intrusion of words and themes from previous conversations" (Orange & Purves, 1996, p.141). Furthermore, Irigaray (1967) noted that in conversation, people with dementia are likely to digress frequently and at length from topics under discussion. Taken together it is clear that dementia has a global impact on conversation as the disease progresses, which creates problems for people with a diagnosis and their potential conversation partners (Table 2.2.).

Table 2.2. Summary of the impact of dementia on global communication at each of the three stages of severity based on MMSE scores (after Kempler, 1995)

Stage of AD	**Associated language deficits**
Mild	• Anomia (word finding difficulties) becomes noticeable • Increased use of semantically empty words, i.e. "stuff" or "thingy" in place of content words. Therefore fluency of language is maintained but content becomes compromised • Comprehension of abstract phrases that requires some degree of inference is poor • Spontaneous language through writing is impaired • Shows difficulty in following complex interactions • Prone to repetition and digression in conversation • Awareness of language difficulties starts to diminish at end of this stage
Moderate	• People with dementia now have increasing difficulty in both producing and comprehending speech

	• Anomia worsens • Use of semantically empty words increases while content words decrease • Pragmatic deficits increase, i.e. poor topic maintenance and pronoun use • Ability to follow instructions is impaired • Ability to produce coherent writing and comprehension in reading is impaired • Conversations become difficult to follow • Individuals with dementia may begin to withdraw from social situations • Appear to be unaware of communication deficits
Severe	• Word and sound substitutions (paraphasias), poor articulation (dysarthria) and lack of coherence render language almost uninterpretable • Speech often characterised by echolalia (repetition of others), palilalia (repetition of self) or muteness • All comprehension of speech is impaired • Can no longer participate in social interactions via language or any other form of communication

Table 2.2. suggests that people with dementia experience a clear and inevitable deterioration of their language and comprehension skills, concluding with the inability to participate in any sort of social interaction with other people. This is the commonly held and asserted view of people with dementia. This assault on the

ability to communicate may be *the* most frustrating and upsetting impact of dementia for both people with a diagnosis and their caregivers is (Azuma & Bayles, 1997). Social situations become increasingly difficult for people with dementia as they forget names, social contexts, recently discussed topics and even words. In turn, professional and family caregivers are faced with the challenge of making themselves understood in the face of their own decreasing ability to understand those they care for (Bayles & Tomoeda, 1991).

2.4. The Social Impact of Dementia and Its Associated Communication Difficulties

Communication problems have significant and far-reaching effects for people with dementia and those who care for them. Those with a diagnosis, their families and professional caregivers all experience great frustration as a result of failed attempts to communicate with each other. However, these difficulties are not solely due to the impact of dementia on the communication of people with a diagnosis. Interpersonal and environmental factors also play a key role in the difficulties encountered by people with dementia and their potential interaction partners.

2.4.1. Impact and interpretation of cognitive changes in dementia

Many difficulties that occur between people with dementia and caregivers arise directly from the cognitive changes that occur as a result of dementia. For example, the WM and executive function problems mean that people with dementia typically require a great deal of prompting from their caregivers. In the early stages this can be checking that activities have been completed and that people are keeping on top of work or daily activities. As dementia progresses, people may need to be

reminded of where they are, what day it is, what time it is and what they were just doing, etc. The constant need for monitoring and reassurance undoubtedly weighs heavily both on people with dementia and their caregivers.

The changes in the relationship with the person who has dementia are particularly significant for family caregivers (Zarit & Edwards, 1999). Where the caregiver is a husband or wife, the transition from partnership to caregiving and dependency is typically very difficult to deal with. For many couples this change occurs after they have spent a lifetime together and thus the caring partner often feels that they have lost the person they have shared their life with. In addition, the increasing physical care that people with dementia require, such as help with going to the toilet and washing, may be embarrassing for the partners or children of people with dementia.

With increased dependency there is typically a shift in dementia care to addressing the physical needs of the person with dementia. Less attention is paid to the social and psychological needs of people with dementia, yet this is arguably the biggest area of need both for the patients and those who care for them. For family members the progressive levels of need are difficult and distressing to deal with. For professional caregivers, people with dementia are increasingly viewed as somehow less than human. This 'dehumanisation' is typical in dementia care (Kitwood, 1990) and may reflect a defensive process on the part of professional carers to distance themselves from the reality of severe dementia.

Relationships can also be affected by the memory problems of people with dementia as they fail to recognise family members and significant events. Relatives feel hurt and rejected by the failure of people with dementia to recognise recent photographs, e.g. of grandchildren (Bayles & Tomoeda, 1991). This could be

because photographs have emotional significance for family members and they expect them to have the same resonances for people with dementia. Consequently, failure to recognise the people or places may suggest to caregivers that they are not important to the people with dementia. It is more likely, however, that people with dementia have either not laid down memories of these recent events or that they cannot access them (Shenk, 2001).

Related to this are difficulties experienced by people with dementia interpreting social situations. Social cognition describes the relationship between social behaviour and the underlying cognitive processes that supports it. Unsurprisingly, people who have cognitive impairments also have difficulties reading cues in social situations. It has been proposed that people with dementia have specific difficulties recognising emotions in other people (Allender & Kazniak, 1988; Testa, 1999). Rapid automatic processing of the six basic, universal, emotions (happiness, sadness, surprise, fear, anger and disgust), is a fundamental component of social communication (Batty & Taylor, 2003). The face and body provide immediate nonverbal indicators of other people's internal states, sending powerful cues as to how they are feeling. Thus difficulty picking up on social cues could lead to misunderstanding and inappropriate behaviour. However, it appears that the problems faced by people with dementia are not so much to do with detecting emotion in others, but rather with interpreting the complex information contained in social situations. Thus they can recognise the six basic emotions from photographs of faces (Astell, Ellis, & Hockey, 2004). However, when faced with interpreting complex social scenes, they are much less likely to make inferences about the feelings and motivations of characters, sticking instead to concrete descriptions of items in the scenes (Astell et al., 2004). This has practical implications for everyday

interactions with friends and family members and is another source of misunderstanding and hurt feelings that arise in the relationships of people with dementia.

2.4.2. Attitudes towards people with dementia

Orange & Purves (1996) noted that the nature of relationships can influence the quality of interactions between people with AD and their conversational partners. Family caregivers find themselves in particularly challenging circumstances, as they are typically provided with very little information about the impact of dementia and little or no training in how to care for someone with the illness (Hepburn, Tornatore, Center, & Ostwald, 2001). Crucially, family members may be unaware that their behaviour has an impact on the person they care for (Kitwood, 1990). Therefore, many of the symptoms of dementia are misinterpreted and may be unintentionally exacerbated by family members (Kitwood, 1997). For example, although personality changes in people with dementia do not always occur or are distinct, especially in AD, family caregivers cite this as one of the most prevalent and distressing symptoms to deal with (Chatterjee, et al, 1992). Indeed even small changes in character or increases in so-called problematic behaviour, such as forgetting, aggression and wandering can cause family caregivers to feel resentment towards their relatives with dementia (Williamson, et al, 2005).

Spouses who become caregivers may have shared decades of life and experiences with the person with AD. This mutually shared knowledge between an individual with AD and his spouse might prevent conversational breakdown and facilitate access, recall and retrieval from autobiographical memory (Palm & Purves, 1996; cited in Orange & Purves, 1996). However, it can also create unrealistic

expectations about what people with dementia should be able to remember. Orange & Purves (1996) called for further analyses of the influences of context-dependent factors on the conversations between people with AD and their spouses. Further research in this area could also go some way towards improving the relationships between people with dementia and their professional caregivers.

More research has been conducted into relationships between formal caregivers and people with dementia. Several studies have reported a relationship between poor attitudes towards people with AD and accounts of high 'burnout' in care staff (Astrom, Nilsson, Norberg, Sandman & Winblad, 1991; Berg, Hansson, & Hallberg, 1994; Chappell & Novak, 1992; Constable & Russell, 1986). Poor motivation and education among staff can lead to reduced levels of staff-resident interactions as staff feel unable and/or unsupported to communicate with people with dementia (Burgio, Engel, Hawkins, McCormick & Scheve, 1990; Carstensen, Fisher, & Malloy, 1995). A lack of knowledge in these areas can often lead to a misinterpretation of the communication attempts of people with AD and therefore, less effort by care staff to interact. This paucity of social contact is undoubtedly detrimental to the individual with AD (Jones, 1972, cited in Lubinski, 1979, p. 241). This highlights the importance of maximising the potential for interaction in the social environment.

Caregiver attitudes and behaviour can be significantly improved by education about the cognitive and social impact of dementia and of the existence of significantly spared abilities in those with a diagnosis (Berg et al, 1994; Constable & Russell, 1986; Chappell & Novak, 1992). Providing information in these areas improves how formal caregivers regard people with dementia, their relationships

with those they care for and their own levels of job satisfaction (Berg et al, 1994; Constable & Russell, 1986; Chappell & Novak, 1992).

Education is also needed to challenge negative expectations caregivers bring to the communication environment. Whilst family caregivers bring their memories and prior relationship to the caregiving situation, there is evidence that professional caregivers have both negative and low expectations about the abilities of people with dementia. This is at the root of the 'malignant social psychology' in dementia care identified by Kitwood (1990; see section 2.4.4). Staff attitudes towards the severity of AD can also have a knock-on effect on staff-resident communication (Burgio, Engel, Hawkins, McCormick & Scheve, 1990; Carstensen, Fisher, & Malloy, 1995). For example, it has been reported that nursing aides use facilitative conversation strategies such as providing reminders, cues and encouragements and have more interactions with residents with early AD than those with more severe AD (Dijkstra, Bourgeois, Petrie, Burgio & Allen-Burge, 2002). These authors argued that it is actually people at the more severe stages of the disease who are in the greatest need of conversational facilitation (Dijkstra, et al, 2002).

2.4.3. Distressed behaviour

Approximately 50% of people with dementia experience changes in their behaviour or the emergence of new behaviour (Zaudig, 2000) such as agitation, anxiety, mood and sleep disturbance (Stoppe et al. 1999). These changes are commonly termed 'challenging behaviour' as they present a challenge to caregivers, both formal and informal. Indeed such behaviour changes are cited as the most common reason for home care to break down (Moniz-Cook et al. 2001) and presents a significant management problem in formal care settings (Bird, 2002). The

occurrence of such behaviour impairs the quality of life of the person with dementia by resulting in exclusion from ordinary everyday activities and through the risks some behaviours pose to staff and fellow residents (Emerson, 1998). Changes in behaviour may also impact on care by diverting staff resources and increasing the pressure on staff to successfully manage the distressed behaviour.

The reason for a behaviour being labelled as 'challenging' is often due to the perception of home carers or nursing staff, and the distress caused by the behaviour, as opposed to the actual behaviour itself (Bird, et al., 2002). However, behaviour such as shouting, following a caregiver or weeping, can be argued to be serving a communication function, indicating to caregivers that a person with dementia is distressed (Stokes, 2000). Stokes (2000) highlighted the need for comprehensive functional analyses to assess the triggers underlying an individual's behaviour, such as potential stressors in the environment or communication of an unmet need, in order to be able to reduce distress in people with dementia and stress in caregivers.

2.4.4. Malignant social psychology

A state of 'malignant social psychology' (Kitwood, 1997) arises as a result of the interaction between the neurological impairments experienced by people with dementia and the negative attitudes of those around them. It is important to point out that in using the term 'malignant' Kitwood (1997) was not referring to any ill intent of caregivers towards people with dementia. Rather malignancy in this context referred to the nature of our "cultural inheritance" (Kitwood, 1997, p. 46). The resulting malignant social psychology is known to have a significant negative impact on the wellbeing of people with dementia and may even hasten further cognitive

decline. Figure 2.2. shows the dialectical process of the neurological impact (NI) and malignant social psychology (MSP) on the person with dementia (Kitwood, 1997).

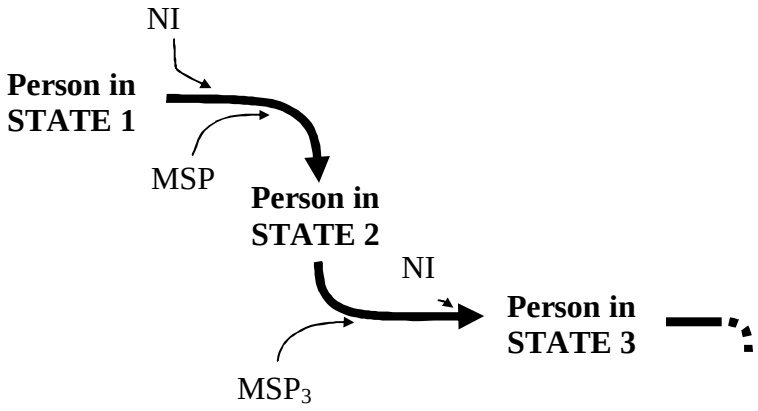


Figure 2.2. How the person with dementia deteriorates from state 1 to 3 as a result of the combination of both the NI associated with the illness and the MSP (Kitwood, 1997, p. 51).

Caregivers' responses to the behaviour of people with dementia are largely dependent on their perceptions of whether people with dementia can exert control over their behaviour (Paton, Johnston, Katona & Livingston, 2004). Paton, et al (2004) recently found that rather than attributing the symptoms of AD to the illness, caregivers believed that most of the symptoms were under the control of those they care for. In short, family caregivers felt that many of the problematic behaviours displayed by their loved ones were premeditated and deliberate (Paton, et al, 2004). As a result of this belief caregivers may engage in behaviour towards the person they care for that subtracts from the personhood of the individual with dementia. These negative caregiver behaviours are known as 'personal detractors' (Kitwood, 1990). These include infantilisation, marginalisation or even completely ignoring people with dementia (Table 2.3).

Table 2.3. Category and description of personal detractors identified by Kitwood, 1997.

Category	**Description**
Treachery	Using forms of deception in order to distract or manipulate a person, or force them into compliance.
Disempowerment	Not allowing a person to use the abilities that they do have; failing to help them to complete actions that they have initiated.
Infantilisation	Treating a person very patronizingly (or 'matronisingly') as an insensitive parent might treat a very young child.
Intimidation	Inducing fear in a person, through the use of threats or physical power.
Labelling	Using a category such as dementia, or 'organic mental disorder' as the main basis for interacting with a person and for explaining their behaviour.
Stigmatisation	Treating a person as if they were a diseased object, an alien or an outcast.
Outpacing	Providing information, presenting choices, etc., at a rate too fast for a person to understand; putting them under pressure to do things more rapidly than they can bear
Invalidation	Failing to acknowledge the subjective reality of a person's experience and especially what they are feeling.
Banishment	Sending a person away, or excluding them – physically or psychologically.
Objectification	Treating a person as if they were a lump of dead matter: to be pushed, lifted, filled, pumped or drained, without proper reference to

	the fact that they are sentient beings.
Ignoring	Carrying on (in conversation or action) in the presence of a person as if they were not there.
Imposition	Forcing a person to do something, overriding desire or denying the possibility of choice on their part.
Withholding	Refusing to give asked-for attention, or to meet an evident need.
Accusation	Blaming a person for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation.
Disruption	Intruding suddenly or disturbingly upon a person's action or reflection; crudely breaking their frame of reference.
Mockery	Making fun of a person's 'strange' actions or remarks; teasing, humiliating, making jokes at their expense.
Disparagement	Telling a person that they are incompetent, useless, worthless, etc. giving them messages that are damaging to their self-esteem.

Predictably, these behaviours by caregivers can be extremely damaging to the self-esteem, self-image and social confidence of people with dementia. For example, in a situation where a family caregiver and her loved-one with dementia are looking at family photographs together, a 'personal detractor' would be created if the caregiver responded to the person with dementia's failure to recognise a photograph of herself, by saying "Don't be daft – that's you, silly!" Kitwood (1997) argued that 'personal detractors' are destructive and that their negative effects last long after their occurrence, resulting in the social withdrawal of people with dementia (Kitwood, 1990).

2.5. Severe Dementia

As dementia severity increases to the point where speech is lost, people with a diagnosis find their communicative bids increasingly ignored or incomprehensible to caregivers (Lubinski, 1995). In the severe stages of dementia, people may also lose mobility and control over basic activities of daily living, resulting in them spending much of their time alone in their bedrooms.

Learned Helplessness Theory (Seligman, 1975) refers to the emotional state experienced when one perceives a lack of control over one's situation or environment. It derived from research into depression and is closely related to Social Breakdown Syndrome (Zussman, 1966; cited in Lubinksi, 1995) within which outward negative perceptions of a person's competence combines with his own pessimistic self-perception. As a result of this, the individual resigns himself to this negative view and accepts his supposed ineffectiveness. Lubinski (1995) applied Learned Helplessness Theory to dementia to illuminate both the experience of dementia and attitudes towards it. For example when people with dementia perceive that their communicative bids and responses are ineffectual, they stop engaging. As mentioned in Chapter 1, people with severe dementia who have all but lost the power of speech are often eventually considered to be 'socially dead' (Sweeting & Gilhooly, 1997). Social death occurs as a result of people in the surrounding environment regarding the person with dementia, although still physically alive, as socially inept, unworthy and effectively dead in respect of participation in the social world.

Given that the attributes of selves 1, 2 and 3 (Section 2.1) are largely communicated through speech, it is easy to understand how people with dementia, who are losing or who have lost the power of speech, are often thought to have

experienced a loss of self as a result of their illness. Sabat & Harré (1992) argued that sense of self in dementia is indicated by the use of first and second person indexical pronouns. However, other authors have argued that the absence or decline of the use of these pronouns in the speech of people with dementia does not necessarily signify the loss of self (Small et al, 1998). Rather, Small et al (1998) posited that the integrity of self is present in people with dementia who are losing speech as they are still able to indicate a sense of self in other ways, such as via non-verbal communication.

In their study of the 'discourse of self in dementia' Small et al (1998) analysed the social interactions that took place between residents of a nursing home with severe dementia and their caregivers. The authors found that more than 50% of the people with severe dementia did not use first person indexical pronouns in their discourse. However, they *were* able to indicate a retained sense of self via conflict. For example people with severe dementia were regularly at odds with members of staff and other residents who asked them to do something they did not want to, e.g. to sit in a particular chair. In such situations, people with severe dementia indicated both their own desires non-verbally (i.e. "I don't want to sit in that chair") and their resistance to the negation of those desires by others. This conclusion fits with Stokes' (2000) theory of distressed behaviour in that displaying one's sense of self via conflict with others may be resultant of a stress reaction elicited by experiencing difficulties in communicating. However, if the person with severe dementia was able to speak clearly, there is no reason to assume that she would not have engaged verbally in the same conflict. Nevertheless, what remains clear from this example is that her refusal to sit in the chair offered to her indicates a definite awareness of her

own desires and a resistance to the desires of others. In effect, she displayed both 'self 1' and 'self 2' attributes very effectively but in a non-verbal manner.

2.6. The Significance of Self in Dementia

If the self is socially constructed, then the main aim of caring for people with dementia should be to preserve their personhood (Downs, 2005; Kitwood, 1997) and self-image. However, the concepts of self and self-awareness are disparate and are defined and discussed according to the subjective perspectives of the authors. The measurement of self-awareness is also a thorny subject as it is largely assessed via the spoken word, implying that when people with dementia become non-verbal they have no sense of self. However, self can also be projected non-verbally (Small et al, 1998).

Maintenance of self-image perhaps becomes more important to the person with dementia as he or she become increasingly positioned or labelled by those they interact with as losing their sense of self. Thus, Sabat (2000) argued that one of the best ways to study dementia and its impact is to examine the everyday social exchanges that occur between those with a diagnosis and healthy individuals. Chapter 3 explores how making use of retained communication skills in people with dementia at all stages of the illness and identifying ways in which these can be maximised might alter the negative social environment they and their caregivers find themselves in.

CHAPTER THREE

RETAINED COMMUNICATION SKILLS AND SELF-AWARENESS IN DEMENTIA: FACILITATIVE STRATEGIES

3.1. Retained Communication Skills: Overview

The communication problems experienced by people with AD are most often conceptualised within the medical model, which focuses upon the diagnosis and descriptions of deficits, impairments and disabilities rather than retained abilities (Kitwood, 1997). This model identifies communication difficulties with the diagnosis of dementia and implies that people with a diagnosis have little ability for communication due to both the degenerative progression of their disease and the significantly impaired capacity for new learning (Orange et al., 1995). Although this medical 'deficit' model predominates in dementia care, in recent years attempts have been made to shift the focus onto uncovering and maximising the communication skills that people with dementia retain (Kitwood, 1997). Predictably, it is most difficult to accomplish this as the disease progresses as their capacity for speech declines and caregivers believe that people with severe dementia simply do not have the ability to communicate (Lubinski, 1995).

The 'person-centred approach' to dementia is used to provide a framework for identifying retained skills across illness progression and exploration of how these can be maximized to support meaningful interactions between people with dementia and caregivers.

3.2. The Person-Centred Approach

The 'person-centred approach' (Kitwood, 1997; Brooker, 2004) to dementia situates the person with dementia at the centre of all aspects of caregiving. The focus is on identifying and meeting the needs of the person, in contrast to the medical model which focuses on identifying and treating symptoms. The person-centred approach aims to enhance well-being by improving relationships and communication between people with dementia, their families and professional caregivers (Moniz-Cook, 2002). This is achieved by taking into account the life experiences and the likes and dislikes of each person with dementia in order to develop a greater understanding of the individual. This in turn allows for care tailored specifically to the individual to take place. As such, a comprehensive approach towards the person with dementia that takes into account her life history is essential. 'Person-centredness' is achieved when carers and family members focus more on the individual than on the illness.

Brooker (2004) proposed VIPS, which are the four main elements that should be addressed in person-centred care:

- **V**aluing people with dementia and their caregivers (V)
- Regarding people with dementia as **i**ndividuals (I)
- Looking at the world from the **p**erspective of people with dementia (P)
- Creating a positive **s**ocial environment so as to allow the person with dementia to experience relative well-being (S).

Any strategy to facilitate communication between people with dementia and their caregivers or to maintain a sense of self in people with dementia should, in theory, contain these essentials. In so doing, the onus is placed very much on the caregiver or advantaged communication partner to ensure that these elements are fully

addressed. The relationship between people with dementia, their family members and professional caregivers (the dementia care triad) is critical for improving wellbeing (Woods, Keady & Seddon, 2008). This highlights the need to explore the nature and quality of relationships between members of the care triad as well as the impact of dementia on individuals with a diagnosis.

3.3. Retained Communication Skills in Mild to Moderate Dementia

Despite significant conversational difficulties, many studies have shown that people with AD retain identifiable communication skills and the desire to communicate. (Astell & Ellis, 2005; Orange & Purves, 1996). In their review of the literature, Orange & Purves (1996) identified a wide range of retained conversational skills and their proposed significance to maintaining social interaction for people with dementia. These included appropriate turn-taking, making requests for clarification and confirmation, repair of misinterpretations, maintenance of conversation topic and referring to themselves using 'I' and 'me'. Findings from Orange & Purves' review and from other authors are cited below (Table 3.1.).

Table 3.1. Retained conversational skills and their significance for social interaction in people with dementia (*cited in Orange & Purves, 1996; **cited in Hopper, Bayles & Kim, 2001; cited in Orange & Purves, 1996 and Hopper, Bayles & Kim, 2001).

Authors	**Strategy/retained ability**	**Value**	
		People with dementia	**Conversation itself**
**Kempler,	Comprehension and	Maintains ability to	Maintains

Curtiss & Jackson, 1987; **Schwartz, Marin & Saffrin, 1979	expression of grammar and syntax at early stages	engage	conversation
***Bayles & Tomoeda, 1994	Sustained attention in early stages	Allows person to follow commands and carry on a conversation	Maintains flow of communication
	Answer open-ended questions in early stages	Allows person to stay on track in conversation	Maintains flow of communication
	Can contribute meaningfully to discussions in early and middle stages	Allows person to maintain status as communication partner	Maintains flow of communication
	Ability to greet, name, converse and express needs in middle stages	Maintains social status	Facilitates 2-way communication
	Ability to reminisce in early and middle stages	Maintains social status and allows projection of self	Facilitates sharing of autobiographical information
	Responding appropriately to a compliment	Maintains self-esteem	Demonstrates appreciation of speaker'

***Bayles et al, 1990; **Fromm & Holland, 1989; ***Ripich et al, 1991	Social aspects of conversation, i.e. greeting and leave-taking	Maintains individual's sense of temporality in conversation	Maintains timing of 2-way conversation
*Richardson & Marquardt, 1985	Imitating partner	Reduces communication load	Maintains conversation
*Richardson & Marquardt, 1985	Assuming role of listener	Reduces communication load	Maintains conversation
*Richardson & Marquardt, 1985	Stock phrases	Reduces communication load	Maintains conversation
Duong, Tardiff & Ska, 2003; *Cardebat, Demonet & Doyon, 1993	Modulations (comments about personal performance during discourse task)	Represents judgements about the difficulty of the task; reflects awareness of impairments; evidence of retained pragmatic abilities	Maintains communicative turn when faced with narrative impairments.
*Ramanathan, 1995	Continuity elements/well-formedness, i.e. sustainers, extensions	Maintains interpersonal social contact	Maintain the interaction
*Bohling, 1991	Correct use of requests for clarification, specification and	Maintains interpersonal social contact	Clarifies interaction

	confirmation		
Temple, Sabat & Kroger, 1999	Intact use of politeness	Maintains interpersonal social contact	Maintains interaction
Sabat & Cagigas, 1997	Extralinguistic Communication	Maintains interpersonal social contact	Compensates for lack of verbal fluency
*Lesser & Milroy, 1993 Perkins, Whitworth & Lesser, 1998	Use of minimal turns such as “mm”, “aha”, “yeah”, “right”. Goodenough & Weiner (1978) refer to these as ‘passing moves’	Removes onus on turn-taking and places on caregiver	Maintains conversation
Perkins, Whitworth & Lesser, 1998	Non-use of repair	Removes threat of cognitive deficit being obvious to others	Maintains interaction
*Garcia & Orange, 1996	Use of the words ‘I’, ‘We’ & ‘Us’	Displays knowledge of ‘self’	Maintains conversation
*Hutchinson & Jensen, 1980; Ripich & Terrell, 1998; ***Ripich, et al., 1991	Able to engage in turn-taking	Retained skill	Maintains conversation

*Bayles & Tomoeda, 1994; *Causino et al., 1994	Late stage participants able to maintain aspects of topic control, turn- taking, use and understanding of presuppositions and directives	Retained skill	Maintains interaction

The communication skills identified above have largely been classified as examples of conversational maintenance strategies. However, they can be further divided into those that serve purely to maintain social interactions (maintenance elements) and those that serve to save face in social situation (face-saving elements). For example, the retained ability to turn-take (Hutchinson & Jensen, 1980; Ripich & Terrell, 1998; Ripich, et al., 1991) indicates a method of maintaining interactions by managing the flow of conversation. In contrast, imitating your partner, assuming the role of the listener and using stock phrases (Richardson & Marquardt, 1985) may be regarded as a means of saving face in social situations (Goffman, 1955, 1959). Rehearsed or formulaic sequences are commonplace in the verbal output of people with AD (Guendouzi & Muller, 2001). Also known as 'stock phrases' (Richardson & Marquardt, 1985), these utterances are typically considered to indicate communicative hardship (ibid.) Although this is almost certainly the case, the use of these phrases also signifies both a desire to continue interacting and a resourceful method of disguising the cognitive burden of generating conversation (Guendouzi & Muller, 2001).

The repetition of ideas is also often present in the conversation of people with AD and three main arguments have been proposed to explain their occurrence. First, that repetition signifies working memory problems (Garcia & Joanette, 1997) and an inability to monitor verbal output and to change mental sets (Schindler, 1984). Second, that these repeated 'scripts' serve as a social mask to hide severe difficulties in keeping track of the conversation (Stewart & Joines, 1987). Third, that the repetition of ideas and seemingly irrelevant topics by people with AD functions to project and preserve a sense of self and maintain social interactions (Lubinski, 1995). More specifically, Lubinski (1995) reasoned that if an idea is discussed repeatedly throughout a conversation even after a topic change has been initiated, reiteration might be an indicator of the importance of the subject matter to the person with AD. Although the occurrence of repetition of ideas is discussed widely throughout the literature (Garcia & Joanette, 1997; Schindler, 1984; Stewart & Joines, 1987; Lubinski, 1995) very rarely have the actual themes and possible significance of repeated narratives been investigated. Such an analysis may provide an insight into the themes important in maintaining and projecting self-image in individuals with dementia.

Imitation or partial imitation of the healthy conversational partner's previous comment by the person with AD is thought to signify an attempt to reduce cognitive load, thereby maintaining conversation and saving face (Guendouzi & Muller, 2001; Richardson & Marquardt, 1985). In Guendouzi & Muller's (2001) study, the investigator asked "How are your granddaughters?" The person with AD replied, "How many granddaughters?" The authors assert that in this particular case, the person with AD may have used partial repetition to compensate for her hearing difficulties. However, it may also have been intended as a time-buying and therefore

face-saving act that might be less embarrassing for the person than making a direct request for repetition, such as “Can you repeat that, please?”

Although the use of imitation by people with dementia undoubtedly alludes to some of the communication problems associated with the illness, one could argue that it also indicates considerable resourcefulness. Richardson & Marquardt (1985) regarded such conversational elements as representing an attempt on the part of the person with dementia to reduce her cognitive load. As such, one can assume that firstly, the person with dementia must be aware of the burden in the first place. Secondly, these strategies also serve as an attempt to cover-up the conversational difficulties the person with dementia is experiencing.

These skills undoubtedly require the orchestration of complex cognitive processes and as such, should not be marginalised. From a social perspective, they allude to both the ability and desire to communicate, and to an untold level of insight and awareness of self-image on the part of people with AD.

Many, if not all of the findings in Table 3.1 are indicative of awareness of conversational difficulties on the part of people with AD. Indeed, several authors have noted that people with AD sustain an insight into their condition up until and some would argue *after* they have reached an advanced level of severity (Astell & Ellis, 2005; McGlynn & Kaszniak, 1991). This insight or awareness is implicit in the use of verbal face-saving strategies in people with AD that serve to mask memory and word finding problems from others. For example, when faced with a direct question a person with AD might use stock phrases, such as “Oh, goodness me!” or engage in distraction activities that might afford them more time to consider their reply such as drawing attention to something outside a window. As discussed in Chapter 1, face-saving strategies are not exclusive to people with AD, and are

employed for the same reasons by healthy individuals (Goffman, 1955, 1959). However, in individuals with AD, face-saving activities allude to conscious awareness not only of their communicative difficulties, but also of their sensitivity to how others perceive them, factors indicative of complex social knowledge and insight.

3.4. Person-Centred Approaches to Improving Interpersonal Communication and Sense of Self in Mild to Moderate Dementia

3.4.1. The Communication Enhancement Model (Orange et al., 1995)

The 'Communication Enhancement Model' was born out of the increasing need for reliable communication strategies for use by care staff. This model emphasises the role of the relationship between people and their environment and the importance of these as significant contributors to health and wellbeing (Orange et al., 1995). According to this model, communication problems arise when there is an imbalance between the person with AD's abilities and motivation and the expectations of caregivers in combination with the opportunities for communication afforded by their surroundings.

This model suggests that care staff should respond to people with AD in a manner that is individually tailored to their communication abilities and requirements. In so doing, this model promotes a person-centred approach to care and aims to empower people with AD. More specifically, the aim of this model is to maximise communicative potential and satisfaction between communication partners and to increase communicative effectiveness on the part of the person with AD (Garcia & Orange, 1996). The model was tested in a single case design within which

members of care staff were trained firstly to recognise the person with dementia as an individual rather than “just a collection of deficits” (Orange et al., 1995, p.30). The staff were also taught to recognise and interpret both verbal and non-verbal communication used by individual’s with dementia they worked with. The training focused on teaching staff to recognise cues that indicated the person’s comprehension of their appropriate use of communication towards her, i.e. direct working and slowly paced messages. In this way, care staff were better placed to understand the communicative bids made by the person with AD and to communicate with her in a way that was meaningful to her.

3.4.2. FOCUSED (Ripich, 1994)

FOCUSED is a caregiver training program incorporating 7 different communication strategies that can be used by caregivers to improve communication between themselves and people with Alzheimer's disease (Ripich, 1994). The FOCUSED programme includes assessment of the caregiver’s level of knowledge of communication in AD and offers training to address misconceptions about the disease, to offer communicative techniques that maximise existing skills and to support caregivers in reaching appropriate expectations of people with AD. Results of a pilot study indicated significant differences in carer attitude towards AD patients and level of knowledge of the disease after training in FOCUSED (Ripich, 1994). Further studies using FOCUSED have shown that after training family caregivers report decreased communication difficulties and increased knowledge of AD (Ripich, Ziol & Lee, 1998). Furthermore, caregivers asked less unhelpful open-ended questions compared to control groups in a longitudinal study of the use of FOCUSED (Ripich, Ziol, Fritsch & Durand, 1999). These results indicate the

benefits of a personalised approach and caregiver training that emphasises retained communication abilities in people with AD and how to maximise them.

3.4.3. Bayles (2003)

Bayles (2003) argued that there are a range of methods that can be used to maximise communication function in people with AD that are based on what we know about the communication and memory deficits in AD. She proposed that since people with AD have a basic working memory deficit, any interventions should be based on reducing the amount of information the individual with AD has to maintain in this memory store (Bayles, 2003). The following basic guidelines were developed from this viewpoint:

1. Minimise the amount of information that the person with AD must maintain in consciousness.
2. Simplify long-term memory search.
3. Simplify the ways in which information must be manipulated (Bayles, 2003).

Table 3.2. Evidence based suggestions for facilitating communicative function in people with AD (adapted from Bayles, 2003).

Suggested area to facilitate	**Proposed facilitative technique(s)**
Work with remaining span capacity	• Give short commands that are easier to remember and follow • Avoid tasks that require the person with AD to remember a series of commands

	• Break instructions into simple units that are given one at a time • Allow the person with AD to complete each component of the task before providing further instruction
Simplify language	• Use simple, active, declarative clauses and avoid embedded relative clauses • Speak at a moderate rate as talking too slowly can put further stress on WM by requiring speech to be held in WM for a long period and talking too quickly can overload WM • Restate any misunderstood information in another way • Use choices or yes/no questions with people who have difficulty with open-ended questions • Use high frequency words • Avoid overuse of pronouns as these require the person to remember antecedents
Provide contextual support for conversation	• Supply an artefact(s) that will provide contextual support in conversation i.e. photographs, objects, books.
Provide repetition	• Provide the opportunity for repetition for information that needs to be maintained/learned
Errorless meaning	• By providing forced-choice recognition tasks,

	people with AD can be prevented from strengthening a memory trace of response error
Priming	• Facilitate responses by the use of prior stimuli
Reduce cognitive load	• Allow the person with AD to do one thing at a time • Support oral instructions with written instructions • Eliminate distractions • Ask individuals to recognise rather than recall

3.4.4. The potential of reminiscence in maximising retained conversational skills and sense of self

One of the most commonly used methods of facilitating communication in individuals with AD is reminiscence. Reminiscence can be defined as the silent or vocal recall of events in an individual's life, either alone, with another individual or with a group of people (Woods, Portnoy, Head & Jones, 1992). In one-to-one situations, reminiscence is usually conducted using photographs. A number of studies allude to the importance of personally relevant reminiscence materials e.g. family photographs in reminiscence with people with dementia. For example, Cohen (2000) argued that family photographs help professional caregivers to improve how they view and comprehend people with late stage AD. By viewing their service users as individuals in other contexts, i.e. in family life, at work or on holiday, professional caregivers are afforded a deeper understanding of those they care for. It has also been suggested that personal photographs aid people with dementia to feel more contented with their current situation by relating to images of people they have loved in the past, thereby providing comfort in an unfamiliar world (Koretsky, 2001). This

process is thought to be particularly beneficial to people with AD because the progressive deterioration of working memory renders it increasingly difficult to hold a conversation based on present or recent events. As such, people with AD can experience feelings of disempowerment by attempting to engage in such communication. By contrast, basing a conversation on past events allows the interaction to focus on retained remote memory in people with AD. Therefore, emphasis is placed on retained capacity (functioning remote memory) rather than deficits (working memory function). Furthermore, taking into account the individual's life history is one of the central tenets of 'person-centred' care (Brooker, 2004).

Reminiscence also makes use of the retained communicative abilities of people with AD. For example, the provision of a conversational topic that the person with AD is comfortable with; i.e. a past event, can make use of her remaining communicative skills (Orange & Purves, 1996). Conversely, the initiation of a conversation that is based on the present or recent past might prevent the person from engaging in the interaction altogether. In short, the use of reminiscence allows people with AD both to participate in conversation on a more equal basis and to make use of their retained memory and communicative abilities.

There are a number of studies that note the value of reminiscence as a communication aid. Indeed, it has been suggested that the primary influence of reminiscence is the positive effect it has on communication in general (Thompson, 1978). For example, reminiscence has been reported to improve social functioning in people with AD (Hern & Weis, 1991; Kiernat, 1979; Gardella, 1985; & Orten et al., 1989; Tabourne, 1991, 1995 in Finnema et al., 1999), improve self-esteem and provide a sense of identity (Dröes, 1991), increase interaction between people with

AD and professional caregivers, and advance staff knowledge of residents (Baines, Saxby & Ehlert, 1987; Goldwasser & Auerbach, 1996; Head, Portnoy & Woods, 1990). Reminiscence is also regarded as an appropriate method of encouraging emotional expression in people with AD (Quackenbush & Barnett, 1995). As aforementioned, remote memory, or memory for events from the distant past appear to remain relatively preserved in AD (Rau, 1993). As such, activities that can tap into this ability may have the capacity to involve people with AD in meaningful interactions.

The above strategies are focused on person centred verbal communication. As such, the remaining skills in each individual are maximised and meaningful communication and mutual understanding is made possible. However as previously mentioned, when people reached the severe stages of dementia they may have little or no retained verbal skills. Therefore, a more creative approach to person-centredness is required.

3.5. Retained Communication Skills and Sense of Self in Severe Dementia

The retained communication skills previously discussed in this chapter are primarily based in verbal interaction. As stated in Chapter 2, when the illness progresses to the later stages, people with dementia may lose the ability to speak altogether. Duffy (1999, p.577) argued that caregivers of people with dementia have an "intuitive dependence on language as a sign of emotional connection". However, he also asserts that our internal experience of the world is not made up of language alone and that there are other ways of understanding human communication. For example, Speech Communication Theory asserts that all behaviours could be construed as communicative and classifies communicative behaviours as such.

Communicating meaning between individuals through nonverbal/subvocal forms can often communicate the subtext of a conversation. As such we attend subconsciously to nonverbal cues such as kinesics (bodily movement), tacesics (touch) and proxemics (orientation and spacing) (Kendon, 1980). Duffy (1999, p.579) stressed that this type of communication is not intended to infantilise the person with dementia. Rather, the aim is to "restore some of the emotional vibrancy in the communication that has been lost or obscured as adults become increasingly dependent on structural logical language".

Subvocal communication is not a well-researched area; however it is regularly operationalised in counseling techniques. For example, counselors are encouraged to sit close by the client to indicate a position of intimacy or to sit forward in their chair to assume an interested position. The use of these behaviours in this situation is based on the notion that often the 'true' meaning of our verbal communication is embedded in accompanying non-verbal signals. Duffy (1999) argued that perhaps the best example of this can be seen in the early exchanges between infants and parents. The structure and the linguistic contents of these exchanges are, for all intents and purposes, meaningless. However, few people would argue that these early exchanges are without meaning or emotion (Papousek, 1995, cited in Duffy, 1999). Duffy (1999) sums up the meaning of such subvocal communication in infant-parent interactions as follows:

> "The parent does not cease to use language because of the limitations in logical exchange. Indeed, language becomes a vehicle to communicate several dimensions within the exchange. This form of nonrational language communicates many things including affirmation, affection, approval,

> reinforcement and at the same time also provides the context in which the emotional bond between parent and child is increasingly stabilised and nourished. As a result, it becomes a difficult and onerous task to maintain verbal communication with an older adult when logical structure is diminished and eventually completely absent. It is not possible, therefore, to learn to reinstate this type of poignant communication between family members and their demented relatives." (Duffy, 1999; p.579).

Duffy's assertion that this type of communication is not intended to infantilise the person with dementia is critical. The aim of focusing on nonverbal communication is to encourage the emotional message in the communication that has been lost or obscured as people become increasingly dependent on structural logical speech. Duffy concludes that "to be able to keep talking, not just nonverbally, to our demented patients allows us to nourish and continue their still existing rich emotional life" (1999, p.579)

Although remote and working memory and language are significantly affected by dementia, there is evidence to suggest that so-called 'emotional memory' remains intact (Duffy, 1999). Neuropsychological evidence for this has been drawn from research on Post Traumatic Stress Disorder (PTSD) in which people experience the loss of the memory of trauma suggests that these memories are lost as a result of frontal cortex memory functions blocking the traumatic memory as a self-protective function. However, midbrain structures still seem to retain relevant memory traces that can be retrieved at appropriate times (van der Kolk & Mc Farlane, 1996, cited in Duffy, 1999). Retained midbrain memory in PTSD is comparable to the pattern of neuropsychological damage seen in the AD brain, which begins in the hippocampus

and then spreads to midbrain and brainstem structures (Duffy, 1999). Duffy (1999) argued that this may be why a person with dementia may be unable to identify a significant person in her life or the nature of their relationship but nonetheless retains an emotional impression of their past relationship. However, Duffy (1999) also noted that this knowledge may be of little consolation to a loved one who has been misidentified.

Kitwood (1997, p75) said "In the course of dementia a person will try to use whatever resources he or she still has available. If some of the more sophisticated means of action have dwindled away, it may be necessary to fall back on ways that are more basic, and more deeply learned; some of these were learned in early childhood". As such, some people at very severe stages of dementia exhibit persistent bodily movements which often involve the stimulation of their own bodies, such as rubbing their leg, chewing their fingers, pulling at items of their clothing or patting either themselves or external objects with their hands (Kitwood, 1997). Perrin (2001) postulated that these behaviours should be regarded as self–stimulatory in nature and occur in response to the failure of the environment to provide the person with dementia with occupation and a feeling of security. As such, the person with dementia retreats into her own world and these repetitive behaviours provide stimulation that possibly represent her "last desperate bid to remain psychologically alive" (Kitwood, 1997, p.75). In the absence of speech, these self-stimulatory behaviours may potentially be used as a basis of communication between people with severe dementia and their caregivers.

3.5.1. Validation Therapy (Feil, 1993)

Validation therapy (VT; Feil, 1993) was developed in the late 1960's as a means of communicating with older people and was directed towards individuals with Alzheimer's disease in the 1980's (Neal & Briggs, 2004). VT is based on recognising and validating the individual's subjective reality. As such, even if the caregiver cannot understand the communication of the individual with dementia, she must act as though she does. This assertion reflects Newson's (1978) 'as-if' theory on the communication between parents and infants (section 1.2). In so doing, the caregiver does not attempt to orientate the person with dementia to present reality; rather she attempts to enter into the person with dementia's world. This principle serves to validate the subjective experience of the person with dementia, thereby valuing his/her emotions. Feil (1993) outlined a set of validation principles for caregivers to follow that embody the main thrust of the theory. For example, all behaviour engaged in by people with dementia must be regarded as having a meaning behind it and the person cannot be forced to change their behaviour. Caregivers are also encouraged to accept each individual non-judgmentally and to view all people with dementia as valuable, no matter how impaired they are (ibid.).

Feil (1993) noted a number of ostensible benefits of validation for people with dementia, including improvements in speech, facial expression, communication with others and reduced need for the use of physical restraints or psychotropic drugs. However, there is a lack of scientific evidence in support of its effectiveness with particular regard to outcome measures (Day, 1997; Neal & Briggs, 2004). Despite this, the basic principles of VT; i.e. maintaining and facilitating residual communicative skills in people with dementia, in themselves suggest that the techniques employed might evoke positive affect and enhance self-esteem. These, in

turn would also have a positive impact on quality of life. Arguably, the constant validation of an individual's emotions and personal reality can allow almost any situation to be meaningful and could also be seen as being supportive of Kitwood's notion of person-centred care (1990). Specifically, VT views the person with AD as a whole person with a history and emotions and attempts to maximise the retained abilities of each individual.

3.5.2. Habilitation Therapy (Raia & Koenig-Coste, 1996)

Habilitation Therapy represents not so much a general approach, but a way of thinking that is geared towards improving the quality of life for people with severe dementia by enhancing their confidence and functional abilities (Raia & Koenig-Coste, 1996, cited in Volicer & Bloom-Charette, 1999). It rests on caregiver perceptions of the person with dementia with regard to his/her maintained psychological function; namely his/her ability to experience and communicate emotions and aims to better understand the global impact of dementia as a whole (ibid.). As such, one of the main aims of Habilitation Therapy is to gain an insight into how individuals with severe dementia communicate and experience the communicative bids of others (Raia, 1999). Raia & Koenig-Coste (1996) draw a distinction between communication and social domains in this model and define differential goals and outcomes for habilitation therapy in these areas.

Within the social domain, the goal is to facilitate the person with dementia to maintain social and cognitive skills via caregiver practice. As such, the caregiver is encouraged to work with and to maximise retained verbal and non-verbal communication skills of the person with dementia. The main desired outcome of this approach is to encourage expression of positive emotions as a result of having a

sense of purpose and engagement in a meaningful activity. Within the realms of communication, Habilitation Therapy aims to facilitate mutual understanding between people with dementia and their caregivers. The desired outcome is to reduce frustration due to verbal difficulties in the person with dementia, thereby encouraging the use of retained communication skills for longer. The use of Habilitation Therapy in the communication domain requires the caregiver to listen intently and to be extremely creative and encouraging. In so doing, the caregiver must endeavour not so much to make sense of the person with dementia's verbal output but rather, the emotional message behind them. Furthermore, the caregiver must use and encourage the use of non-verbal communication as a method of facilitating retained communicative abilities in the person with dementia.

3.6. The 'Collaborative Personhood Model'

The impact of dementia on communication is a complex domain, influenced by the specific effects of degeneration interacting with environmental factors. It is clear that as dementia progresses, although people experience many identifiable difficulties there are equally a range of retained functions. The identification and development of these remaining skills could increase the probability of mutually rewarding interactions occurring between people with AD and their carers. Moreover, by making use of these retained skills by engaging in collaborative communication, carers and other interactions partners can facilitate the expression and maintenance of self-image in people with dementia. Consequently, any intervention that aims to promote communication in people with AD must target these relatively intact functions (Azuma & Bayles, 1997). As such, for people with mild to moderate dementia, communication may be focused on activities that are

speech based. However, for people with severe dementia who have little or no retained speech, non-verbal strategies must be used in order to achieve mutually meaningful interactions. These possibilities are explored in the following empirical chapters.

Previously discussed models of communication and personhood (sections 1.2 -1.6) have taken into account the collaborative nature of communication and personhood. However, mutual understanding is achieved in the models via verbal communication. For example, in 'the between', in Buber's (1937) 'I-Thou' relationship holds all co-created human entities such as the self, communication and *language* (Anderson & Ross, 1994; cited in Thomlison, 1982). However, in the absence of language, 'the between' must be achieved by non-verbal methods and mutual understanding and personhood must remain unspoken in a verbal sense. This may be begun by the advantaged communication partner remaining open to the communicative behaviours of disadvantaged communicator. The advantaged communication partner must then attempt to use those identified communicative behaviours in order to learn and use the language of the disadvantaged communicator. As such, the advantaged communicator uses his "creativity to establish a new channel of communication" (Kitwood, 1997, p.3.) and as such strives to achieve the 'least collaborative effort' (Clark & Wilkes-Gibb, 1986).

The following model of communication and personhood combines vital elements of previously discussed work by Rommetveit (1974), Vygotsky (1978), Trevarthen (2001), Buber (1967) and Clark & Brennan (1991). However, this model is not focused on verbal communication and proposes that 'the between', 'intersubjectivity' and 'personhood' can also be achieved via non-verbal communication. Non-verbally, 'the between' will not include shared experiences that

are verbalised, rather it is more likely to involve the shared expression of emotions. Nevertheless, for the ultimate aim of personhood to be achieved either verbally or non-verbally the communication between interaction partners must be collaborative in nature.

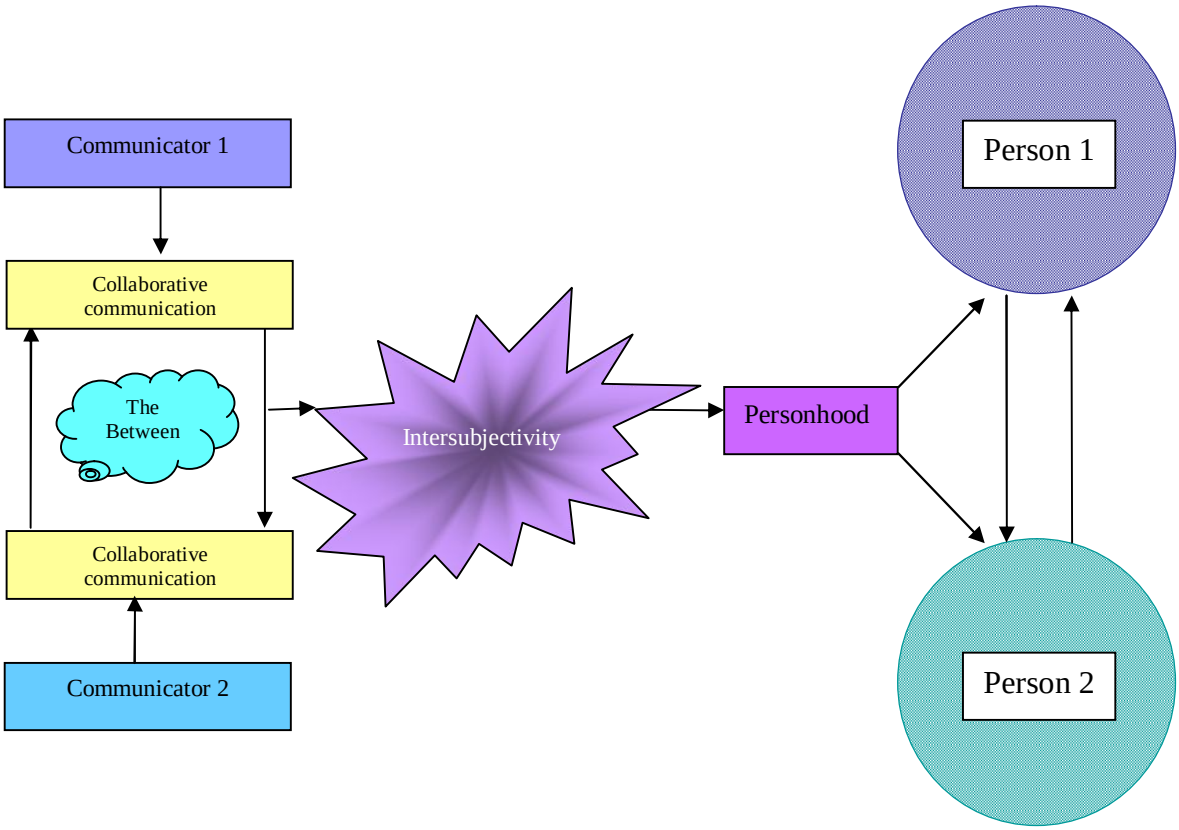


Figure 2.3. The 'Collaborative Personhood Model'.

As seen in figure 2.3, communicator 1 and communicator 2 both engage in verbal or non-verbal collaborative communication in order to share the 'the between'. From this process develops 'intersubjectivity' or an understanding of each other. This mutual insight leads both parties to consider each other as people in every sense, therefore mutual 'personhood' is granted. This model will form the basis of all research and discussion on communication in people with dementia and will hereafter be referred to as the 'Collaborative Personhood Model'.

3.7. Ethical Framework

3.7.1. Ethical process

All of the research reported in this thesis was carried out in accordance with the relevant BPS Code of Ethics and Conduct, including the most recent version (2006). Each of the studies reported in this thesis followed the same basic ethical procedures. First of all, contact was made with managers of care homes and day centres and each proposed study discussed with them. On agreement that their facility would participate in any given study, managers were asked to identify potential participants from their list of residents/clients. Information sheets and consent forms were then sent out to these individuals and/or their family caregivers (in the case of nursing home residents) via the participating service providers. It is important to note that at this stage the investigator did not have access to any of the names or any other contact details of potential participants. These details were only disclosed to the investigator if positive responses, including contact details, were returned. On receipt of consent forms the investigator planned a timetable of research with the manager of the participating service providers and all people with dementia and their relatives were informed of the planned procedures and the studies explained to them. In studies 1 and 2 all participants were able to consent to participate. In studies 3,4 and 5 the severity of the participants' dementia was such that they were unable to give consent themselves and a relative or proxy was asked to give consent.

At all times the welfare of the participants was of paramount importance. To ensure their needs were kept to the fore, consent was sought before, during and after sessions were carried out, with participants frequently asked if they wanted to continue or finish. This process of continual consent helped to ensure that participants took part only if they wanted to. In cases where potential participants

were unable to give informed consent staff and family members were invited to observe interactions in order to ensure that participants were not displaying signs of distress.

3.7.2. Ethical background

During the seven years that the research presented in this thesis was carried out, a number of changes in legislation relating to ethical procedures occurred. The most significant was the passing into law of the Adults with Incapacity (Scotland) Act 2000 (AWI(S) Act), which largely came into force in April 2001. However, Part 5, Medical treatment and Research, did not come into force until summer 2002.

Within Part 5, Section 51, Authority for research, details the conditions and circumstances for conducting research with participants who under the AWI(S) Act 2000 are judged unable to give consent. Where the other conditions are met, consent must be "obtained from any guardian or welfare attorney who has power to consent to the adult's participation in research or, where there is no such guardian or welfare attorney, from the adult's nearest relative."

The first three studies in this thesis commenced prior to the implementation of Part 5 of the AWI (S) Act 2000. At this time there was no national ethical process and projects were subject to local review procedures. Participants in the first three studies were all clients of Dundee Social Work Department and they gave approval for the studies. This was sought in connection with the umbrella project, CIRCA (Computer Interactive Reminiscence and Conversation Aid) which the first three

studies reported here were carried out as part of. All documents relating to the studies can be found in Appendix 1.

3.7.3. Main ethical issues

In all cases the investigator based her work in the four Ethical Principles laid out by The British Psychological Society Code of Ethics and Conduct, March 2006. These Principles constitute the main areas of responsibility of the psychologist, i.e. 'Respect, Competence, Responsibility and Integrity'.

Informed consent

The main ethical issue which arose in respect of participants in this thesis is their ability to give consent. For those potential participants deemed unable to give consent within the terms of the AWI(S) Act 2000 guardians/welfare attorneys/nearest family members were asked for their consent for the investigator to approach the participants. These representatives were also invited to be present during the interactions to ensure that the person with dementia was willing to engage with the investigator.

People with advanced dementia are typically excluded from the social world and as such are very rarely consulted about any aspect of their care or treatment. This situation is sadly, commonplace. Therefore, it seems unethical to exclude these individuals from research that attempts to engage them socially simply because they experience difficulties in communicating verbally and are thereby unable to give informed consent.

Video recording and photographs

It may be argued that video recording or photographing people with dementia without their own informed consent is unethical. For example, one might argue that recording a person with dementia represents an invasion of his/her privacy. However, in all cases permission to video record participants was granted either by people with dementia themselves (in cases where informed consent was possible) or their closest family member (in cases where informed consent was not possible). It is our responsibility as researchers to make the most of the data we collect as people have given their time and effort to our studies. Furthermore, if the research is to have an impact and an application in a real world setting then it would be unethical not to record it in some way. For example, microanalysis or interrater reliability of both verbal and non-verbal interactions would not be possible without having access to video recordings of the communication.

CHAPTER FOUR

STUDY 1 - THE IMPACT OF DEMENTIA PROGRESSION ON PERSONHOOD AND THE CONSTRUCTION OF SELF

4.1. Introduction

The collaborative model of personhood recognises the social nature of self and how the behaviour of other people impacts on the construction of self. This study examines the social interactions of people with mild to severe dementia and a communication partner to explore the relative impact of dementia on self.

The urge to communicate and the development of self-awareness are critical for humans to function as social beings. The urge to communicate is apparent at birth (Meltzoff & Moore, 1983; Valenza, et al., 1996), and once speech has emerged this facilitates development of awareness of self (Haden, 1998), through interactions with parents, siblings and, later in development, peers. As such, children learn about who they are by interacting with others and co-creating with them social roles in a range of environments and situations.

The emergence of so-called face-saving strategies in social situations further highlights the social and interactive nature of self-awareness. Face-saving strategies are conversational behaviours such as changing the topic of conversation if one is unsure or uncomfortable or using humour in the face of embarrassment that signify both an awareness of ourselves as individuals and an awareness of how others view us (Goffman, 1955; 1959). This reflects both the social nature of self-awareness and the importance of speech in communicating this. However, the presence of speech is not a requirement for the attribution of self-awareness as infants (Meltzoff & Moore, 1983)

and patients with acquired aphasia after stroke are still considered to be self-aware (Sundin, Norberg & Jansson, 2001).

People with dementia, however, who experience progressive decline in speech and communication skills, are frequently described as lacking or losing awareness (Duffy, 1999). One reason for this is the definition of awareness commonly applied in dementia, which has focused on examination of a person's level of awareness of his/her cognitive and communicative decline (Aalten, van Valen, Clare, Kenny & Verhey, 2005) rather than referring to awareness of self as an entity. On this criterion it is commonly suggested that people experience a loss of insight into their cognitive difficulties by the moderate stage of the illness (McDaniel, Edland & Heyman, 1995), although there is some evidence that awareness of conversational difficulties is present at the later stages of the illness (Mayhew, Acton, Yauk & Hopkins, 2001). This is supported by evidence of the continued use of verbal face-saving strategies such as imitation (Richardson & Marquardt, 1985) and conversational fillers (Ramanathan, 1995) by individuals with AD. Although the presence of these strategies does not refer explicitly to the person's awareness of their conversational difficulties, this certainly suggests implicit awareness. This raises the question of how far into the disease process these strategies, and proxy measures of awareness, are available and used by people with dementia.

A second issue in studying the impact of dementia on self-awareness is the relative reliance of measures of assessment on speech (Chapter 2.1.). Given the impact of dementia on speech-based communication this has implications for assessing the impact of dementia on self-presentation and self-awareness, particularly in the most severe stages of the illness when speech may be gone. This raises the question of whether assessment is actually measuring the impact of dementia on speech or on self

and may explain why the study of awareness of the personal or social self in people with dementia has been relatively overlooked (Downs, 2005) with the exception of Sabat's (2001) work examining evidence for the retention of sense of personal self (Self 1), personal attributes (Self 2) and socially-presented self of social roles and identity (Self 3: See Chapter 3). This work however, is primarily focused on speech-based analysis and recent calls for greater use of nonverbal measures in the assessment of self may help to address this issue (Aalten et al., 2005; Clare, et al., 2005; Downs, 2005).

A related complication in studying self-awareness in dementia arises from the negative attitudes experienced by people with dementia from people they interact with. This is critical given the social nature of self-image and -awareness. Although loss of speech does not equate to loss of self, people with dementia frequently encounter attitudes suggesting that the 'person' has gone (Duffy, 1999) rendering them 'lesser beings'. For example, Brock (1993) likened people with severe dementia to dogs "since they supposedly lack capacities for hopes and fears, dreads and longings for their futures" (cited in O'Neill, 2003; p281).

Such dehumanising attitudes influence the way people with dementia are treated (Kitwood, 1991). However, caregivers may also hold negative beliefs about the degree of awareness and control that people with dementia have over their actions, expressed in the assertion that people with dementia sometimes deliberately behave 'badly' (Paton, et al, 2004). This highlights the complex relationship between the views and behaviour of others and the challenge of maintaining identity and sense of self, faced by people with dementia.

This study aims to examine the impact of dementia on communication and awareness of self using a naturalistic conversational approach based around

reminiscence. As aforementioned (section 3.4.4.) reminiscence has been identified as a particularly useful social activity for people with dementia. Basing a conversation on past events, allows the interaction to maximise their retained memory for remote events in their life and their communication skills, such as turn-taking and topic maintenance (Orange & Purves, 1996), whilst minimising reliance on their memory for recent events (Astell, et al., 2008). However, communicative difficulties common to the moderate stage of dementia such as the repetition of ideas and themes can often impede the process of reminiscing with others.

Caregivers may interpret repetitions and so-called 'off-target verbosity' (Gold, Andres & Arbuckle, 1994) as evidence that they are not being listened to and thus to regard 'normal' conversation with a person with dementia as longer feasible (Astell, Ellis, Bernardi, Bowes, Tunnard & Webb, 2005). As previously discussed, three main arguments have been proposed to explain the occurrence of repeated themes in the conversation of people with dementia (section 3.3.) although very rarely have the actual themes and possible significance of repeated narratives been investigated.

4.1.1. Study aims

This study serves as a first step in examining how the progression of dementia impacts on the experience of self–image and personhood of those with a diagnosis. The study uses a dyadic situation whereby the person with dementia interacts with a partner, in this case the investigator. The use of the conversational situation is intended to provide insight into the impact of dementia on both communication skills and self-awareness in relation to another person. In this study, the communication partner uses a collaborative personhood approach to communication (section 3.6.) which is designed to be supportive.

As such the study is designed to examine the conversational strategies employed by people with dementia to both maintain interactions (maintenance strategies) and to save face (face-saving strategies) in social situations. This design also allows the contents of the interaction to be examined for recurring narrative themes (ReT's) and their possible significance to the maintenance and projection of self by individuals with dementia. The influence of the behaviour of the communication partner on the person with dementia can also be examined, by assessing the style and number of facilitative strategies used during the reminiscence sessions.

Research questions:

1. Does the use of maintenance strategies change as the disease progresses?
2. Does face-saving behaviour change as dementia progresses?
3. Does the repetition of themes indicate maintenance and projection of self by people with AD?
4. How can the interaction partner facilitate communication and personhood?

4.2. Method

4.2.1. Participants

Participants were recruited from four dementia care facilities, one operated by a charity and three operated by the local Social Work department. Information sheets and consent forms were sent to potential participants and their family carers. When these forms were returned the study was explained to the person with AD and they were asked to give verbal and/or written consent. Twenty-one people (seven men) with probable AD based on the NINCDS-ADRDA criteria (McKhann et al., 1984) consented to take part in the study.

The participants ranged in age from 56 to 97 years (mean = 81.42, SD = 11.12). All participants were native English speakers of predominantly Scottish origin.

4.2.1.1. Ethical approval

Ethical approval for this study was gained under that granted to the Computer Interactive Reminiscence and Conversation Aid (CIRCA) Project.

4.2.1.2. Ethical procedure

Contact was made with managers of the participating day care centres and the proposed study was discussed with them. On agreement, managers identified potential participants from their list of residents/clients. Information sheets and consent forms were then sent out to these individuals and their family caregivers via the participating service providers. On receipt of consent forms the investigator planned a timetable of research with the manager of the participating service providers and all people with dementia and their relatives were informed of the planned procedures and the studies explained to them.

Participants were given absolute consideration at all times. Consent was sought before, during and after sessions were carried out, with participants frequently asked if they wanted to continue or finish. Continual consent helped ensure participants took part only if they wanted to.

4.2.2. Materials (see Appendix III for an example of the photographic materials)

Photographs were used as visual prompts in the study as they are commonly used in reminiscence activities with people with dementia. The photographs depicted

images of a range of annual events regarded to be relevant to the backgrounds and culture of the participants. These were: Christmas, Burn's Night, Easter, New Year, birthday and holiday. Three image types represented each annual event: food, people and scene, giving a total of 18 photographs. For example, there was a Christmas pudding (food), children opening Christmas presents (people) and a Christmas tree with presents underneath (scene). Each image was presented in either black and white or colour formats giving a total stimuli set of 36 items.

The stimuli were divided into sets of 6: one of each event, 2 of each image types and 3 each of both colour formats. The presentation of each photograph was preceded by either a 'specific' (containing a cue word) or 'general' (not containing a cue word) prompt. For example, the specific prompt might be: "Here is a picture of a Christmas *scene*. What are your memories of Christmas?" Whereas, the general prompt in this case would be: "What memories come to mind when you look at this picture?" These prompts were selected so as to represent a reminiscence-based conversation within which it would be unlikely that the each photograph would be introduced in the same way. However, the inclusion of 2 different types of prompt afforded a modest amount of control over the design.

4.2.3. Procedure

The Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975) was used to provide a measure of dementia severity (see Appendix II). The cut-off point for healthy participants is between 26 and 30 (Folstein, et al, 1975). The participants scores ranged from 7-24 (mean = 14.23, SD = 5.24) indicating a broad spread of dementia severity. Based on their MMSE scores the participants were divided into three severity groups:

21-25 = ‘Mild’ (3 participants/14.3%)

11-20 = ‘Moderate’ (13 participants/61.9%)

0 -10 = ‘Severe’ (5 participants/23.8%)

All participants were literate and had an average of 9.33 years of schooling. The Schonnel Graded Word Reading test (SGWR; Schonnel, 1971) was used to provide an estimate of pre-morbid IQ (see Appendix II). This test requires the participants to read aloud from left to right each from a list of 100 words which become progressively more difficult. Each correctly pronounced word is given one mark and a predicted pre-morbid IQ score is then attributed to that figure. For example a raw score of 1 is equal to a predicted pre-morbid IQ of 45 and a raw score of 100 is equal to a predicted pre-morbid IQ of 115. A range of scores from 73-111 was produced (mean = 76.95, SD = 39.21). However, the lower scores were thought to be unrepresentative of pre-morbid IQ and were taken as a measure of current vocabulary and verbal functioning. This is supported by a positive correlation between the MMSE and SWGR scores ($r=.40$; $n=21$; $p<.05$). Four participants were unavailable to complete the SWGR test and as such were regarded as missing data.

A member of staff brought each participant along to the room where the session would take place. The participants were told that they would be asked a few questions then invited to have a chat with the investigator. It was then explained that the session would be recorded for the purpose of analysis and they were asked to give written and/or verbal consent. All reminiscence sessions were conducted in a designated unoccupied room within each of the four participating care facilities. Each room was set out to allow the participant to sit opposite the researcher at a table.

Following the administration of the Mini Mental State Examination (Folstein, et al., 1975) and the SGWR (Schonnel, 1971), each participant was shown each of one

set of six photographs in turn. Each participant saw two photographs containing food, two containing people and two scenes. Colour and black and white photographs were alternated, as was the use of 'specific' and 'general' prompts. The participants were invited to discuss whatever memories came to mind in response to the photographs with no time limit on how long they could talk.

The communication partner responded to the conversation turns of the participants with dementia, did not disagree with anything they said and provided guidance if the participants became confused, asked for instruction or indicated that they had forgotten what was being asked of them. All reminiscence sessions were recorded using a Sony Walkman Professional, WM-D6C and a Sony Mini DV Video camera.

4.2.4. Coding of verbal responses

People with dementia

Each conversation was transcribed and coded for participants' maintenance strategies (Table 4.1), which are actions made by participants to keep the interaction going. The coding categories were developed from the literature (Ch 3) and a pilot study using transcripts not included in this study.

Table 4.1. Operational definitions of maintenance strategies in the conversations of people with dementia

Conversation Element	**Operational Definition**
Turn-taking	Number of *all* types of turns in response to photographs
Use of minimal turns	Single word turns
Maintaining partner's involvement	Questions that do not require the provision of new information of the interaction partner

Requests for information	Any question that requires any type of further information from the interaction partner
Modulations	Any comment made by the person with dementia about her performance during the task
Story-telling	Any combination of three or more utterances that *narrates* a general or specific single or recurring situation or event from the person's own experience. Either seemingly related *or* unrelated to the stimulus topic
Recurring theme	Topic introduced and reintroduced after a *new* topic has been initiated whether by the person with dementia or the interaction partner

The transcripts were also coded for face-saving strategies describe efforts to mask any difficulties or embarrassment. Again, the coding categories were developed from the literature (Ch3) and a pilot study using transcripts not included in this study (Table 4.2).

Table 4.2. Operational definitions of face-saving strategies in conversations of people with dementia

Conversational Element	**Operational Definition**
Fillers	A *single* sound or word which does not give meaning to the utterance
Imitation	Any utterance that repeats one or more strategies of what has just been said by the interaction partner
Descriptor	Any comment that refers to either all or a single detail of items in the photograph or the photograph itself either directly or indirectly: including *reading* and *counting* from the photograph

Stock expressions	An expression used more than three times in response to stimuli that does not add meaning to the utterance, e.g. “Oh well” or “So, there you are”.
Topic change	Any instance within which the person abruptly changes the subject of conversation
Singing/reciting	Any instance of singing or reciting verse

Interaction partner

The turns of the interaction partner were also examined in the transcripts. The following coding categories were developed from the literature (Ch 3) and a pilot study using transcripts not included in this study (Table 4.3).

Table 4.3. Operational definitions of codes applied to interaction partner’s conversational turns

Conversational Element	**Operational Definition**
Turn-taking	Number of *all* types of turns in response to photographs
Bringing person back to the task	Redirecting the person to the task
Reiterating information	Repeating information or a question, etc when the person does not hear or understand
Indicating continued interest	Short conversational turns that do not add information to the conversation but signal that the other person is still listening/interested
Offering information of self	Offering personal info without being asked
Closed questions	Question that requires a yes or no answer
Open questions	Question that requires more than a yes or no answer
Answering question	Directly answering a question asked by the person with dementia
Laughing	Partner laughs

Commenting on person's input	Conversational comment, e.g. "That's good".
Agreeing with persons comment	Agreeing with person's opinion, statement
Imitation of person with dementia	Interaction partner imitates person with dementia, either a phrase or a word
Reassuring	Interaction partner reassures person with dementia
Indicating contents of picture	Interaction partner highlights the contents of the picture

The following excerpt illustrates the application of the two coding systems to the transcripts:

Participant 7: Christmas/scene/ colour - gp

Investigator: "What memories come to mind when you look at that picture?"

(Facilitative - Open question)

Participant 7: "Pardon?"

(Maintenance – Request for information)

I: "What memories come to mind when you look at that picture?" (Facilitative - Reiteration)

P: "Me sit, me with my brother."

(Face-saving – Descriptor)

I: "Hmmm."

(Facilitative - Continued interest)

Face-saving strategies = when the participant is unsure, unclear or unable to respond.

Maintenance strategies = any utterance that serves to keep the conversation going.

Facilitative strategies = strategy used by the investigator to help the participant to communicate and maintain a sense of self.

4.2.5. Interrater reliability

Responses of people with dementia

Prior to the coding of the transcripts 3 independent raters discussed the practicalities of the coding categories and their operational definitions at length. To examine the efficacy of the categories the raters also used a practise transcript that was not included in the final data set. On reading the transcripts, two of the coders experienced some difficulty in translating the colloquialisms that appeared frequently throughout the transcripts. This led to the development of a glossary of local terms to facilitate inter-rating. The practise transcript, coding scheme and glossary were combined and produced as a coding instruction booklet for the coders (Appendix IV).

Each of two independent raters coded 50% of the transcripts for maintenance and face-saving techniques. A third rater coded 50% of the transcripts coded by each of the independent raters allowing an item-by-item coding agreement to be calculated for each coding category in 50% of all transcripts. Spearman's rho for maintenance strategies codes was 0.78, 0.8 for face-saving strategies codes and 1.0 for 'ReT's'.

Coding of ReT's

Thematic analysis was used to examine recurring themes into Sabat's (2001) categories of self (see Chapter 2.1.):

Self 1 – The self of personal identity, i.e. the presence of 'first person indexical pronouns' such as 'I', 'me', 'mine' or 'my' (Sabat, 2001, p.278). However, for the purposes of this analysis the first person plural, i.e. 'we', 'our' and 'ours' will also be included as indicators of an intact self 1.

Self 2 – The self of mental and physical attributes, i.e. being good at maths and having a good sense of humour or having a slim figure and having blue eyes. As indicated in Chapter 3, some of these attributes may change (e.g. having a slim figure) and some may remain constant (e.g. having a good sense of humour).

Self 3 – The socially presented selves or personae, i.e. the different versions of self that are constructed in different social situations. For example, one person might be a wife, a mother, a child, a teacher and a friend. The crucial element of these personae is that they are constructed only with the cooperation of others (see Chapter 3).

The analysis also took into account the type of memory each ReT represented with regards to life period and emotional valence. For example, was the memory related to an early life event or was if of a memory of their own children? Was it a happy, sad or neutral memory? These additional data were included in order to flesh out the preservation and projection of self-image and to further uncover why this particular theme might be so significant to each individual.

Responses of interaction partner

Prior to the coding of the transcripts 2 raters discussed the practicalities of the coding categories and their operational definitions at length. To examine the efficacy of the categories the raters also used a practise transcript that was not included in the final data set. One rater coded 100% of the transcripts for facilitative techniques and

a second independent rater coded 14% of the transcripts allowing an item-by-item coding agreement to be calculated for each coding category in 14% of all transcripts. Spearman's rho for facilitative elements was 1.0.

4.2.6. Data analysis

People with dementia

The total occurrence of each element for each participant was divided by the number of turns in order to control for variance in the amount of speech produced per individual. This provided a score for each participant in each coding category representing the amount that behaviour occurred per turn. As the data did not meet the requirements for inferential parametric statistical analysis (i.e. an unequal amount of participants in each severity grouping and a large amount of variance) non-parametric Kruskal-Wallis analyses were conducted to look for differences in the usage of conversational maintenance and face-saving strategies between the participants with mild, moderate and severe dementia. Both story-telling and ReT's were calculated in terms of lines of dialogue rather than as number of occurrences. ReT's were analysed thematically providing a qualitative analysis of their content. Stories were analysed as any combination of three or more utterances that *narrates* a general or specific single or recurring situation or event from the person's own experience. Either seemingly related *or* unrelated to the stimulus topic.

Interaction partner

The total occurrence of each facilitative strategy used by the interaction partner was divided by her number of turns in order to control for variance in the amount of speech she produced in response to each individual. This provided a score for each

participant in each coding category representing the amount that behaviour occurred per turn. As the data again did not meet the requirements for inferential parametric statistical analysis (i.e. an unequal amount of participants in each severity grouping and a large amount of variance) non-parametric Kruskal-Wallis analyses were conducted to look for differences in the usage of facilitative strategies used by the interaction partner in response to participants with mild, moderate and severe dementia.

4.3. Results

People with dementia

4.3.1. Maintenance strategies

All of the participants reminisced in response to photographs of annual events and their recollections formed the basis of a one-to-one conversation. Research question 1 asks "Does the use of maintenance strategies change as the disease progresses?" The results showed that all three groups of participants used maintenance strategies in their conversation (Table 4.4). The number of conversational turns was highest in the mild dementia group (55.33) and lowest in the severe dementia group (40) but this difference was not statistically significant. The average occurrence of minimal turns and modulations were very similar across all the three stages of dementia progression (Table 4.4.).

Table 4.4. Means and standard deviations of number of occurrences per turn of maintenance strategies for participants with mild, moderate and severe dementia.

Stage of Dementia	**Mild**	**Moderate**	**Severe**	**Total**
N	N = 5	N = 13	N = 3	N = 21
Maintenance Strategies	Mean Median Range (SD)	Mean Median Range (SD)	Mean Median Range (SD)	Mean Median Range (SD)
Conversational turns	55.33 48.00 34-84 (25.79)	51.38 52.00 18-107 (25.79)	40.0 42.00 13-80 (26.5)	49.23 48.00 13-107 (23.65)
Use of minimal turns	0.13 0.11 0.06-0.24 (0.08)	0.13 0.08 0.03-0.67 (0.04)	0.12 0.75 0-0.37 (0.02)	0.13 0.08 0-67 (0.03)
Requests for information	0.11 0.14 0.05-0.15 (0.05)	0.13 0.07 0-0.38 (0.11)	0.08 0.05 0.02-0.15 (0.05)	0.12 0.10 0-0.38 (0.09)
Maintaining partner's involvement	0.18 0.26 0.02-0.26 (0.14)	0.06 0.05 0-0.21 (0.06)	0.08 0.04 0-0.33 (0.13)	0.08 0.05 0-0.33 (0.09)
Modulations	0.03 0.02 0.01-0.06 (0.02)	0.02 0.01 0-0.06 (0.02)	0.04 0.02 0-0.15 (0.06)	0.02 0.01 0-0.15 (0.03)

The participants with moderate dementia made slightly more requests for information than the participants in the mild and severe dementia groups but not significantly so (Table 4.4). The participants with mild dementia also produced more

behaviours intended to maintain their conversations partner's involvement (0.18) relative to both the moderate (0.06) and severe (0.08) groups (Table 4.4). However, the Kruskal-Wallis analysis indicated no significant differences between the three groups (p>.05).

Table 4.5. Means and standard deviations of number of occurrences per lines of dialogue for stories and ReT's for participants with mild, moderate and severe dementia.

Stage of Dementia	**Mild**	**Moderate**	**Severe**	**Total**
N	N = 5	N = 13	N = 3	N = 21
Maintenance Strategies	Mean Median Range (SD)	Mean Median Range (SD)	Mean Median Range (SD)	Mean Median Range (SD)
Lines of dialogue	95.33 85 55-146 (46.37)	87.76 73 18-177 (49.27)	55.8 55 14-128 (45.73)	81.23 66 14-177 (48.05)
Stories (divided by lines of dialogue)	0.29 0.21 0.14-0.52 (0.2)	0.24 0.22 0-0.64 (0.21)	0.11 0.07 0-0.36 (0.13)	0.22 0.21 0-0.64 (0.19)
ReT's (divided by lines of dialogue)	*0 0 0 (0)	*0.11 0.06 0-0.36 (0.13)	0.03 0 0-0.17 (0.07)	0.07 0 0-0.36 (0.12)

***p<.05**

Of the participants 23.8% did not tell any stories and there was no significant difference between severity groups in a Kruskal-Wallis Test for story-telling (p>.05).

However many of the participants related sometimes very detailed and personal accounts of past events and situations containing evidence of self and self-awareness.

Of the participants 52.4% did not produce ReT's. There were no recurring themes in the conversation of people with mild dementia (Table 4.5) but there were 0.84 ReT's per lines of dialogue of the output of people with moderate dementia. A Kruskal-Wallis Test indicated a significantly higher mean of recurring themes in the moderate than in the mild severity group ($p<.05$).

4.3.2. Face-saving strategies

Research question 2 asked "Does face-saving behaviour change as dementia progresses?" The results showed that all participants used face-saving strategies in their conversation, irrespective of their level of cognitive impairment. Descriptors were the most evident face-saving strategies across all three dementia severity groups (mean = 0.45 per turn). The mild group used them more (mean = 0.82) than the moderate group (mean = 0.45; Table 4.6), with the severe dementia group using them the least (mean = 0.26) but these differences were not significant ($p >.05$). Fillers were also quite common (mean = 0.38 per turn; Table 4.6), with the severe group using these the least (mean 0.27) although again the differences were not significant ($p>.05$). Although less prevalent, stock expressions (0.08 per turn), imitation (0.07 per turn) and topic change (0.03 per turn) all occurred in the conversation of people at all three levels of dementia severity. Only singing and reciting failed to occur across the three groups (Table 4.6).

Table 4.6. Means and standard deviations of number of occurrences per turn of face-saving strategies for participants with mild, moderate and severe dementia.

Stage of Dementia	**Mild**	**Moderate**	**Severe**	**Total**
N	N = 5	N = 13	N = 3	N = 21
Face-Saving Strategies	Mean Median Range (SD)	Mean Median Range (SD)	Mean Median Range (SD)	Mean Median Range (SD)
Descriptor	0.82 0.82 0.5-1.14 (0.21)	0.45 0.40 0.15-1.26 (0.30)	0.26 0.23 0-0.65 (0.23)	0.45 0.40 0-1.26 (0.32)
Fillers	0.46 0.47 0.13-0.79 (0.33)	0.40 0.30 0-1.73 (0.43)	0.27 0.23 0-0.64 (0.23)	0.38 0.29 0-1.73 (0.37)
Stock expressions	0.09 0.12 0.03-0.13 (0.05)	0.08 0.03 0-0.41 (0.11)	0.06 0 0-0.35 (0.15)	0.08 0.03 0-0.41 (0.11)
Imitation	0.06 0.05 0.06-0.08 (0.01)	0.08 0.06 0-0.2 (0.06)	0.05 0.05 0.01-0.09 (0.03)	0.07 0.05 0-0.2 (0.05)
Topic change	0.03 0.02 0.02-0.06 (0.2)	0.03 0 0-0.23 (0.06)	0.01 0 0-0.07 (0.03)	0.03 0.01 0-0.23 (0.05)
Singing/Reciting	0.0098 0 0-0.03 (0.01)	0.01 0 0-0.08 (0.02)	0 0 0 (0)	0.009 0 0 (0.02)

4.3.3. Story-telling and the construction of self-image

In order to explore the presentation and awareness of self in the conversation of people with dementia the stories were further analysed for evidence of Sabat's (2001) three aspects of self: personal self (self 1), personal attributes (self 2) and socially-presented self of social roles and identity (self 3). Some of the stories were clearly related to the stimuli in front of them and others were not, as illustrated in the following examples. The first is the response of a participant in the moderate dementia group, who had an MMSE score of 12, locating him towards the severe end of the group. His first response served to clarify that this was not a personal photograph before going on to relate a long story totalling 72 turns (36 each) of his camping holidays as a young boy (Example 1).

Example 1

Participant 7 – Photograph 4: Holidays/people/black and white – specific prompt

Turn 1. Interviewer: *"Here's a picture of people on holiday. What are your memories of holidays?"*

Turn 1. Participant 7: "Two persons on holiday. They're not connected to me (self 1) at all. What is it you want me to tell you?"

2. I: *"What are your memories of holidays?"*

2. P7: "I (self 1) had some great holidays."

3. I: *"Hmmm."*

3. P7: "Camping."

In this first part of the transcript the participant begins by identifying the contents of the photograph *(descriptor),* and then informs his conversation partner that he is not related to the people in any way. The participant then asks the interviewer what she would like him to tell her *(request for information).* Once the interviewer has repeated the question, the participant then continues with his response informing her that he had experienced "some great holidays…camping." This response was clearly directly related to the specific stimuli (on-topic) and did not shift at all throughout the entire transcript (see below).

19. P7: "And er, we (self 1) used to have a sing-song."

20. I: "Hmmm."

20. P7: "And cars coming down used to join in. And we (self 1) had a great time. And then, we (self 1) used to invite the girls that we had picked up in the dancing."

21. I: "Hmmm."

21. P7: "To come and get a meal. And they came. And we (self 1) gave them a good meal. And then er, we (self 1) sat and blethered. About everything and a'thing. And there was a camp of lassies in the next tent to us. And you've never seen a mess of faces in all your life. They let the sun get at their face."

22. I: "Hmmm."

22. P7: "Oh, and the smell! Oh, a boy came in and he came flying out. I (self 1) says what's to dae with you? He says, go in and see. I (self 1) says no, there's something there, in there that you don't he says your faird to go in. I (self 1) says, I'm no' faird. I (self 1) went away in and I've

(self 1) never done a dafter thing (both laugh). The smell off their faces, ken? (Both laugh) Oh, we (self 1) had some wonderful times. Twelve of us (self 1)."

With regards to self, the above example indicates references only to self 1; the self of personal identity.

The following excerpt (Example 2) provides an example of where a participant is prompted to tell a story that does not appear to be directly related to the stimuli at hand. In this instance the participant, who was also in the moderate dementia group (MMSE = 17), viewed a picture related to Burns Night.

Example 2.

Participant 1 Photograph 5: Burns Night/people/colour – general prompt

Turn 1. Interviewer: *"What memories come to mind when you look at this picture?"*

Turn 1. Participant 1: "Oh, Haggis, Burns supper. That's the Burns haggis and that's the boy playing the pipes. He's sticking the, the thingy in the haggis. Does he play the pipes?" (Laughs)

2. I: *(Laughs) "Yeah."*

2. P1: "We (self 1) had a piper down here. Was it in here? Is this (name)?"

3. I: *"Here? No, this is the (name)."*

3. P1: "It must have been the (name) we (self 1) had it."

4. I: *"Right."*

4. P1: “But er something happened and we (self 1) didn't get our drink or anything. There wasn't enough folk there so she said we'll get it on Tuesday past. And I (self 1) have this cold. I (self 1) couldn't even go out. I (self 1) got down in the bus. The (name) bus. It took me (self 1) right to the door. And er that was alright because I (self 1) was never outside really and er och it was a good laugh if nothing else. I'm (self 1) thinking of that drink! (Both laugh) Of course my (self 1) brother (self 3) had been away down to Glasgow and he came home, you know, walking. (Both laugh) Oh, it was a laugh if nothing else.”

5. I: “Good.”

5. P1: “We (self 1) had haggis on Tuesday past with the tatties, tatties and neep.”

6. I: “Oh aye.”

6. P1: “So it was good. And when we (self 1) were coming away out they said there's, we (self 1) don't have time for a drink. I (self 1) says oh (both laugh). So we (self 1) were all supposed to come yesterday. I (self 1) couldn't come because of this and I (self 1) didn't want to smit everybody else. So my (self 1) mother (self 3) said no, you're not going, so.”

7. I: “Oh well.”

7. P1: “Not with the cold.”

8. I: “No.”

8. P1: “Because there was once, one night somebody left the window open in my (self 1) room and it was gusting, the wind was gusting in and I

(self 1) couldn't get out of bed to tell anybody. So I (self 1) just had to lie there. She got a telling off though but it made no difference."

9. I: *"Yeah."*

9. P1: "Aye well that's the that's an awful wee, wee haggis (investigator laughs). That wouldn't have done much."

10. I: *"No, it wouldn't go around many people."*

10. P1: "No, you'd get a quarter." (Laughs)

11. I: *"Aye, about that."*

11. P1: "Yeah it's nice."

12. I: *"OK, would you like to move on to the next one?"*

12. P1: "Yes please."

Example 2 indicates use of both self 1 (the self of personal identity) and self 3 (the socially presented selves or personae).

Both of the above examples, whether regarded as topic-relevant or off-topic allude to either significant information about the individual or of the experience of emotions.

4.3.4. ReT's and the construction of self-image

The recurring themes in the stories were examined for lifetime period, emotional valence, relevance to self and total number of repetitions (Table 4.7). All but one of these recurring themes was recorded by participants in the moderate group.

Table 4.7. Emotional valence and number of repetitions of recurring themes in the stories told by people with different levels of dementia severity.

Stage of Dementia	**Lifetime Period**	**Theme**	**Evidence of self**	**Emotional Valence**	**Total Repetitions**
Moderate	Early family life	Helping her father with his job on a farm	Self 1 Self 2 Self 3	Positive	2
Moderate	Working life	Working as a children's nurse	Self 1 Self 2 Self 3	Positive	2
Moderate	Adult family life	Bringing up children	Self 1 Self 2 Self 3	Positive	2
	Interests	Being a golfer	Self 1 Self 2 Self 3	Positive	2
	Opinions	Dislike of foul-mouthed language/music	Self 1 Self 2 Self 3	Positive	2
Severe	Achievements	Going to college/getting an education.	Self 1 Self 2 Self 3	Positive	2
Moderate	Early family life	Domestic abuse	Self 1 Self 2 Self 3	Negative	3

Moderate	Adult family life	Having been married in the summer	Self 1 Self 2 Self 3	Positive	3
Moderate	Current life	Always being alone	Self 1 Self 2 Self 3	Negative	3
Moderate	Early family life	“There were six of us.” (Referring to siblings)	Self 1 Self 2 Self 3	Positive	3
Moderate	Adult family life	Having three sons of her own	Self 1 Self 2 Self 3	Positive	4
	Early family life	Her mother remarrying after her father died	Self 1 Self 2 Self 3	Negative	6
	Early family life	Her and her siblings being a “nuisance” to her sister/grandmother /step father	Self 1 Self 2 Self 3	Negative	7
	Early family life	Sister getting married whilst being under her care	Self 1 Self 2 Self 3	Neutral	8
	Early family	Death of father	Self 1	Negative	11

	life	during the First World War	Self 2 Self 3		
	Early family life	Death of mother when she was a child	Self 1 Self 2 Self 3	Negative	14

Out of the 126 recollections (21participants x 6 photographs), there were 74 instances of recurring themes. The majority of instances of recurring themes were negative (44) rather than positive (22) or neutral (8). The following excerpt illustrates a negative theme that was clearly of great significance to the participant (Example 3).

Example 3.

Participant 2. Photograph 3. New Year/food/black and white – specific prompt

Interviewer: "Here's a picture of food that you might have at the New Year."

Participant 2: "Cake."

I: *"What are your memories of the New Year, 'A'?"*

P2: "We (self 1) lived in (name of town) in a quiet place."

I: *"Hmmm."*

P2: "Just, nothing. There wasn't much drinking at our (self 1) house. But my (self 1) father (self 3) made up for it. And he made up to hit my (self 1) mother (self 3)."

I: *"Right."*

P2: "So there was one time he hit. He'd been drinking and he gave her an awful beating. And she was lying on the floor and couldn't get up.

> And I (self 1) just walked out the door and that was the end of it. Here was 'D.J' and WR, the police. He says (participant's name), what are you doing up here at I (self 1) says well, my (self 1) dad (self 3) hit my (self 1) mum (self 3) and she's lying on the floor and she can't get up. Would you help me (self 1) He says, come with me, come on. He says (father's name), do you ken where you're going tonight? He went, you're going along to Bank Street. He says, we've heard about this and couldn't get it. But now we see - she's lying on the floor. So they got a stretcher and took her away."

As in example 2, example 3 provides evidence of both self 1 and self 3 but not self 2.

This was a very personal and emotional topic for the participant to discuss with a relative stranger, which was brought up several times during the session. This story highlights the unpredictability of reminiscence - i.e. it is not possible to predict what sorts of recollections will be prompted by any given stimuli, however, apparently innocuous.

Research question 3 asked "Does the repetition of themes indicate maintenance and projection of self by people with AD?" As with story-telling, the ReT's were examined for evidence of Sabat's (2001) three aspects of self: personal self (self 1), personal attributes (self 2) and socially-presented self of social roles and identity (self 3). As seen in Table 4.8, all participants who produced ReT's provided evidence of selves 1, 2 and 3 in their dialogue. As such, the subject matter of the repeated themes can theoretically be construed as central to the maintenance of and projection self-image to others. The following excerpt illustrates a response containing all three aspects of self (Example 4).

Example 4

Participant 5: Photograph 1: Christmas/people/black & white/specific prompt

Participant 5: “But I've (self 1) always loved children (self 2). But I (self 1) worked a lot with children on the district (self 3).”

Investigator: “Uh-huh.”

P5: “You know, I (self 1) was a district nurse (self 3). And er, I (self 1) never got away from the children. I (self 1) always liked the children before the adults (self 2).”

I: “Yeah.”

P5: “Because the children were so intense in saying what they wanted and how they could explain it. And, and they were wonderful. It was great.”

In this excerpt awareness of selves 1, 2 and 3 is indicated by the use of first person pronouns throughout, indicating an awareness of the self 1 – personal identity. Second, this participant spoke of her love of children, which served to indicate the presence of self 2 - mental attributes. Finally, the existence of self 3 was confirmed by Participant 5’s mentioning her role as a district nurse. In short, this recurring theme allowed Participant 9 to express her love of children and of the nature of her job. This theme was of obvious importance to her identity and formed a major part of her life. It was also apparent that this participant was proud of her role, which also played a significant role in her sense of identity. Within the realms of the Collaborative Personhood Model, it becomes the role of the advantaged communication partner to validate and encourage this self 3 persona.

4.3.5. Interaction partner

Research question 4 asks "How can the interaction partner facilitate communication and personhood?" The results showed that the investigator used facilitative strategies in response to all participants with dementia and that the amount of each strategy was irrespective of the level of cognitive impairment. Indicating continued interest was the most prevalent facilitative strategies across all three dementia severity groups (mean = 0.33 per turn). The investigator used these most often with the mild group and moderate groups (both means = 0.36) than the severe group (mean = 0.21; Table 4.8), but these differences were not significant ($p > .05$). Reassuring was also used quite frequently (mean = 0.17 per turn; Table 4.8), and was used as a facilitation strategy most often in response to the severe group (mean = 0.28) although again the differences were not significant ($p > .05$). Less prevalent facilitation strategies were laughing (0.08 per turn), open questions (0.14 per turn), closed questions (0.09 per turn), referring to the contents (0.09 per turn), agreeing (0.05 per turn), directing back to task (0.05 per turn), commenting (0.04 per turn), answering (0.04), reiterating (0.01 per turn), imitation (0.01 per turn) all occurred in the conversation of people at all three levels of dementia severity but again the differences between levels of severity was non-significant (p-values $> .05$). Only offering information of self failed to occur across the three groups (Table 4.8).

Table 4.8. Means and standard deviations of number of occurrences per turn facilitation strategies used by the interaction partner for participants with mild, moderate and severe dementia.

Stage of Dementia	**Mild**	**Moderate**	**Severe**	**Total**
N	N = 5	N = 13	N = 3	N = 21
Facilitative Strategies	Mean Median Range (SD)	Mean Median Range (SD)	Mean Median Range (SD)	Mean Median Range (SD)
Turn-taking	60.33 53 38-90 (26.76)	55.76 54 24-113 (23.1)	44 47 19-82 (24.96)	53.61 52 19-113 (23.44)
Bringing person back to the task	0.025 0.026 0.01-0.04 (0.013)	0.05 0.044 0-0.11 (0.036)	0.067 0 0-0.02 (0.087)	0.051 0.041 0-0.21 (0.050)
Reiterating information	0.0126 0 0-0.04 (0.021)	0.0239 0 0-0.13 (0.039)	0.0067 0 0-0.02 (0.009)	0.0182 0 0-0.13 (0.032)
Indicating continued interest	0.367 0.342 0.28-0.48 (0.099)	0.367 0.386 0.12-0.57 (0.127)	0.213 0.166 0-0.56 (0.216)	0.3308 0.365 0-0.57 (0.156)

Offering information of self	0.008 0 0-0.03 (0.015)	0.001 0 0-0.02 (0.004)	0 0 0 (0)	0.002 0 0-0.03 (0.006)
Open questions	0.108 0.113 0.06-0.16 (0.51)	0.135 0.123 0.08-0.25 (0.050)	0.186 0.127 0.07-0.32 (0.109)	0.143 0.125 0.06-0.32 (0.069)
Closed questions	0.054 0.011 0-0.15 (0.084)	0.111 0.079 0-0.31 (0.118)	0.093 0.1053 0.02-0.13 (0.039)	0.098 0.086 0-0.31 (0.099)
Answering question	0.071 0.044 0.04-0.13 (0.052)	0.050 0.035 0-0.14 (0.044)	0.020 0.020 0-0.04 (0.019)	0.046 0.036 0-0.14 (0.042)
Laughing	0.107 0.111 0.08-0.13 (0.026)	0.087 0.732 0-0.34 (0.082)	0.075 0.042 0-0.17 (0.075)	0.087 0.078 0-0.34 (0.073)
Commenting on person's input	0.079 0.094 0-0.14 (0.073)	0.037 0.036 0-0.07 (0.024)	0.055 0.024 0-0.17 (0.066)	0.047 0.036 0-0.17 (0.044)

Agreeing with persons comment	0.0500 0.0377 0.03-0.08 (0.025)	0.0410 0.0192 0-0.18 (0.053)	0.0780 0.0426 0-0.25 (0.104)	0.0511 0.0333 0-0.25 (0.064)
Imitation of person with dementia	0.0226 0.0111 0-0.06 (0.029)	0.0167 0 0-0.08 (0.025)	0.0105 0 0-0.05 (0.023)	0.0160 0 0-0.08 (0.024)
Reassuring	0.1373 0.1333 0.09-0.18 (0.045)	0.1371 0.1667 0.02-0.29 (0.083)	0.2800 0.2553 0.10-0.52 (0.174)	0.1712 0.1667 0.02-0.53 (0.119)
Indicating contents of picture	0.0663 0.0755 0.04-0.08 (0.019)	0.0834 0.0796 0.04-0.13 (0.028)	0.1627 0.1915 0.04-0.25 (0.083)	0.0998 0.0796 0.04-0.25 (0.057)

4.4. Discussion

This study examined the dyadic conversations of people with dementia and an interaction partner to explore the impact of dementia on the experience of self-image and personhood. The investigation was guided by four research questions and the results are discussed in relation to each question in turn.

1. Does the use of maintenance strategies change as the disease progresses?

The desire to maintain and extend interactions was manifest in all participants across the three levels of dementia severity and did not change or reduce significantly. The use of minimal turns by the participants such as “Mhhm”, “Right” and “OK”, served to return the conversational floor back to the conversation partner whilst observing the rules of successful conversation. These behaviours are described as ‘passing moves’, which serve both to remove the onus of the conversation from people with AD whilst maintaining the interaction (Lesser & Milroy, 1993; Perkins, Whitworth & Lesser, 1998).

Requests for information, such as “What is that?” by people with AD have previously been identified as serving to clarify the interaction (Bohling, 1991). Furthermore, asking questions such as these illuminates an awareness of the expectations of others, in this example indicating the knowledge that the conversation partner required a response of some kind. Similarly, although modulations referring to personal performance or the task itself were few, their very existence reflects the complexity of communication skills, self-awareness and social knowledge that are retained by people with AD (Duong, et al, 2003). The occurrence of questions that did not require the provision of new information of the conversation partner (maintaining partner’s involvement) was represented by phrases such as “That’s a nice flower, isn’t it?” or “He’s a handsome guy, eh?” People with AD used these to ensure the conversation partner’s continued engagement in the interaction without demonstrating the wish for her to take control of it. As such, these questions indicated that the participants needed to be aware that they were being listened to, which again alludes to knowledge of self, other and of the norms of social interaction.

2. Does ‘face-saving’ behaviour change as dementia progresses?

All participants used face-saving behaviour in their interactions. The most commonly occurring were descriptors, where participants describe aspects of the photograph, and fillers, where participants make a single sound or word that does not give meaning to the utterance. The use of descriptors by people with AD was particularly illuminating. It was clear that the participants described elements within the images when they were unsure of what they were being asked to do. Arguably, the participants may have forgotten the aim of the task and instead of drawing attention to this by making a request for information or using a modulation, they used descriptions of the images. In this way descriptors not only bought the participants some time to reconsider the nature of the task, they also served to conceal their uncertainty from their interaction partner. This finding reflects that of Astell et al. (2004) and suggests that people with AD use descriptors to indicate the knowledge that the individual is in some respect being evaluated by the conversation partner.

Although less commonly used, stock expressions, imitation and topic change also indicate a significant level of self-consciousness in people with AD. The use of stock expressions by people with AD has previously been described as a means of reducing communicative load in the face of communicative hardship (Richardson & Marquardt, 1985). These phrases represent well-rehearsed scripts that are used in order to both mask cognitive difficulties and to continue interactions. Similarly, imitation has previously been identified as a means of reducing communication load whilst maintaining conversation (Richardson & Marquardt, 1985). It could also be argued that the participants used imitation, especially repeating the last word said by

the interaction partner, to maintain their grip on the social world from which they are increasingly excluded as their symptoms accelerate (Astell & Ellis, 2006).

3. Does the repetition of themes indicate maintenance and projection of self-image by people with AD?

As previously discussed (see sections 3.3. & 4.1.), three main arguments have been proposed to explain the occurrence of repeated themes in the conversation of people with dementia. First, that repetition signifies working memory problems (Garcia & Joanette, 1997) and an inability to monitor verbal output and to change mental sets (Schindler, 1984). Second, that these repeated 'scripts' serve as a social mask to hide severe difficulties in keeping track of the conversation (Stewart & Joines, 1987). Third, that the repetition of ideas and seemingly irrelevant topics by people with AD functions to project and preserve self-image and maintain social interactions (Lubinski, 1995). The results of this study with regard to repeated themes suggest that despite working memory difficulties, people with dementia have the ability to tell stories that are both emotionally charged and relevant to the maintenance of self.

Repeated themes were evident in the stories told by people with AD. Although 'off-target verbosity' is thought to be typical in conversation at the moderate stage of the illness, arguably this is also a time when people with AD are attempting to maintain their self-image in the face of the difficulties they are experiencing. Indeed, all of the recurring themes produced referred either to emotionally salient events, situations or opinions that in essence, served to maintain self-image. There was also a clear range of emotional valence in the contents of the recurring themes with themes ranging from extremely positive topics such as getting married, having a

family and getting an education to particularly negative subjects such as death, domestic abuse and social isolation.

The presence of recurring themes or ‘repetition of ideas’ in the conversation of people with AD undoubtedly highlights some of the difficulties these individuals have in conducting conversations. However, the actual contents of these repeated themes appear to hold significant emotional credence.

4. How can the interaction partner facilitate communication and personhood?

The communication partner in this study provided a supportive and non-judgemental position throughout the interactions. All references to selves 1, 2 and 3 made by people with dementia were acknowledged and the reality of the participants was accepted without question. As such, the advantaged communicator collaborated with the people with dementia using their language to achieve the ‘least collaborative effort’.

4.5. Conclusion

The participants in this study produced many detailed and emotional stories recounting experiences from across their lives. The stories ranged between accounts of a few turns and the detailed recollections of Participant 7 of the holidays of his youth, which lasted more than six minutes. Participant 7 clearly enjoyed telling his story and spoke readily of emotions, of friends and family and of specific situations with obvious pleasure. Given that this participant had an MMSE score of 12, placing him at the lower end of the moderate dementia severity group, previous literature would suggest that any stories he told would be less detailed and specific in nature and would be more off topic than the story he produced. So, how could an individual

at this stage of dementia be able to produce such a story? One might argue that this story was well-rehearsed over the years and as such the participant reeled it off in a habitual manner. However, this participant had never told this story to any of the care staff before and no strategies of it later appeared as recurring themes in his transcript.

The reminiscences of people with AD, in particular individuals with moderate and severe AD were sometimes 'off-target'. This observation could be explained in a number of ways. For example, more severely impaired participants may not have fully understood the particular detail of the task and their deviation from the subject may have reflected this. Secondly, these participants may have comprehended the detail of the task but may have retrieved memories that are more abstract, leading them to talk about seemingly unrelated topics. Thirdly, these participants way have been uncertain of the task but made full use of the one-to-one time with another person by taking the opportunity to communicate.

The results of this study have implications for the ways in which we regard awareness on the part of people with AD. Although previous work on this subject has suggested that individuals with AD lose awareness or insight into their illness, clearly they do not lose awareness of the effects of the disease. The current study has shown that even in the severe stages of the illness, people with AD retain an awareness of their communicative difficulties. For example, on being asked what memories came to mind on looking at one of the photographs, a participant with severe AD replied; "Oh, I don't have any memories of this, no I can't think of anything. I must be getting older." Although in saying this, the participant did not explicitly mention her illness, she explicitly spoke of her interpretation of the memory difficulties she was experiencing.

This example reinforces the potential of reminiscence to open up channels of communication between caregivers and people with dementia. However, it is apparent that stimuli can prompt people in unexpected ways to recollect incidents from their lives. The findings suggest that where people with dementia are allowed to discuss whatever comes to mind, they can express opinions and emotions that may be crucial to their maintenance of self-image. Slavish adherence or constant redirecting to the topic introduced by the communication partner would serve to undermine this.

The findings of this study also highlight the complexity of studying the impact of dementia on social interaction and self-awareness. All of the participants responded verbally in the reminiscence sessions and demonstrated both a capacity for self-expression and a desire to interact with others. In some cases, the contents of conversation were perhaps less important than the interaction itself. In these cases the act of reminiscing allowed the participants with dementia to interact closely with another individual and to maintain contact with the social world. Instances of story-telling and recurring themes alluded to a desire to maintain social contact and an ability to express emotions, both happy and sad and to discuss issues of particular importance. Face-saving strategies in the conversation of the participants indicated a high level of self-awareness and awareness of the expectations of others. The results of this study indicated that this complex social knowledge is retained even in the later stages of AD.

These findings also have significant practical implications in that this type of reminiscence situation clearly provides a platform for individuals with AD to express themselves emotionally. This, as Kitwood (1997) argued, may be potentially very

rewarding for people with dementia and also for people they interact with as a reminder of their continued personhood.

4.6. The Relevance of this Study to the 'Collaborative Personhood Model'

The view of communication as a socially collaborative process that occurs between interaction partners is central to this study. Although the main focus was on the verbal contributions of participants with dementia, it is important to note that the communication partner adopted an encouraging and accepting position throughout the interactions. For example, the interviewer did not challenge anything that was said by people with dementia nor did she negate any of the versions of self projected by the participants. In other words, the communication partner facilitated the interaction by cooperating with the participants in order to co-create the social process. In their day to day interactions, people with dementia are likely to meet more critical reactions from family and formal caregivers who correct mistakes and point out memory failings.

The next study explores in more depth the impact of the advantaged interaction partner on collaborative communication in a similar conversation-based scenario. However, the partners in this case will be family members of the participants and the stimuli used will be the personal photographs of the people with dementia.

CHAPTER FIVE

STUDY 2 - THE IMPACT OF FAMILY MEMBERS ON THE COMMUNICATION BEHAVIOUR AND SELF-AWARENESS OF PEOPLE WITH DEMENTIA

5.1. Introduction

The previous study has indicated that people with mild to severe dementia maintain both the desire and the ability to engage in social interactions. The study also highlighted indicators of retained self-awareness and the ability to maintain and project self-image in the same individuals. This process was facilitated by the communication partner's knowledge of the impact of dementia and resulting maintenance of collaborative communication throughout the interactions.

Collaborative communication is typically lacking in the daily lives of people with dementia. People with dementia are often subjected to the negative influence of an absence of training and understanding of their illness on the part of their professional caregivers. As such, they experience the unwitting creation of 'Personal Detractors' (Kitwood, 1990) by their caregivers. As described in Chapter 2 (section 2.4.4.), personal detractors are defined as any caregiver behaviours towards the person they care for that subtracts from the personhood of the person with dementia. Much research has been conducted on the negative impact of personal detractors on the self-esteem of people with dementia (Kitwood, 1990).

Most of the research conducted on *family* caregivers of people with dementia focuses on the impact of caregiving on their own health and wellbeing (Zarit & Edwards, 1999). Less is known about how family members communicate with their loved-ones with dementia or how the very nature of their prior relationship might

impact on these interactions. Given the importance of the behaviour of their partner in interactions to people with dementia, it would be expected that interactions with family caregivers would have a different quality to interactions with formal caregivers. The existence of a prior personal relationship could be beneficial and facilitate communication and support people with dementia in the maintenance of self. However, it also possible that prior relationships could have a negative influence on interactions between family caregivers and their relatives with dementia, either through the expectations that these prior relationships give caregivers, or the emotional investment they have in the relationship or an interaction of both these factors.

This study sets out to explore these issues by examining interactions between family caregivers and their relatives with dementia. Using a similar design to Study 1, people with a diagnosis of dementia and a family member will each reminisce individually with the investigator to a set of personal photographs selected from their family album. This part of the study will provide a measure of the amount and type of information provided by each partner about the family photographs. In the second part of the study each pair will then look at the photographs together to explore the social interaction between them.

5.1.1. The use of personal photographs in reminiscence

The use of family photographs in reminiscence with people with dementia is thought to improve how professional caregivers view those they care for (Cohen, 2000). However, less is known of how this activity is conducted with family members and how this might affect interpersonal communication. We can assume that a significant amount of specific details such as names, dates and locations might

be attached to family photographs. Furthermore, if a family member were to select photographs for her and a loved-one with dementia to discuss we could also suppose that she would choose the images according to how significant she considers them to be to the person with dementia. Therefore, it is not unreasonable to think that family members might bring with them a certain amount of preconceptions as to what the person with dementia will remember or wish to discuss in response to these images. Perhaps, then, the impact of the person with dementia failing to recognise a family member in a photograph could be more negative to herself and to her family member than it would be if she were looking at the photographs with a non-family member. These issues are undoubtedly related to the expectations and perceptions that might surround the use of family photographs in a reminiscence situation.

5.1.2. Awareness and the impact of expectations and perceptions

Clare et al (2005) noted a salient issue that is crucial to this study in particular, i.e. the distinction between perceived and actual awareness. These authors proposed that our opinions of the level of awareness of people with dementia are dependant on our expectations of their abilities. Undoubtedly, our expectations are in turn dependant on our own level of understanding of the neurological and psychosocial impact of dementia. Therefore, a care home manager who is fully trained in all aspects of dementia is likely to have a very different view of awareness in her residents with dementia to that of their untrained family members. Downs (2005) proposed that our understanding of awareness in dementia hinges on our own awareness of the impact of the illness and is therefore "relationship-specific" (p.410). Evidently, our knowledge of awareness in dementia also impacts on how we conduct ourselves in social situations with those with a diagnosis. For example, in a

social setting the trained care home manager is likely to act very differently towards her residents with dementia than their untrained family members. Of course, we might expect this as the nature of the personal relationships between the parties will undoubtedly be very different. However, we also know that the impact of these different approaches will have a knock-on effect on the self-esteem and self-image of people with dementia (Kitwood, 1997).

5.1.3. Study aims

The focus of this study is to explore how the impact of personal relationships and mutual expectations impact on the behaviour of people with dementia and their family caregivers. By examining the response of the person with dementia to their personal photographs with the investigator and then with a family member, it should be possible to explore the influence of the interaction partner on the behaviour of the person with dementia. The verbal and non-verbal responses of people with dementia and their family caregivers will be examined in both conditions. Verbal output will be coded so as to identify the amount of specific and 'relevant' detail elicited in response to the photographs, i.e. the correct and inaccurate identification of people, places and story-telling. These data will be collected to assess the knowledge and self-perception of the person with dementia in situations where they are with and without their family caregivers. Furthermore, the dyadic situation will be examined for the occurrence of any 'personal detractors' between caregivers and people with dementia.

Research questions:

1. Will the presence of family caregivers influence how their loved ones with dementia respond to the photographs? If so, in what way does this manifest?

2. Will the presence of relatives with dementia influence how their family caregivers respond to the photographs? If so, in what way does this manifest?

This study used a within participants design. Each person took part in an Individual session (participant and investigator) and a Dyadic Condition (both participants and investigator). The independent variable was the conversational partners involved (Individual and Dyadic) and the dependent variables were the types of information provided and communicative behaviours that occurred between conditions (section 5.7).

5.2. Method

5.2.1. Participants

People with dementia

Five people with dementia (one male) were recruited from a local day-care facility. They were approached through the care facility and provided with information about the study. Each participant was encouraged to discuss the study with his or her family before agreeing to take part. Participants ranged in age from 74 to 91 years (Mean = 82.8, SD = 6.53). Four of the participants had a diagnosis of Alzheimer's disease and one had a diagnosis of multi infarct dementia. The Mini Mental State Examination (Folstein, et al., 1975) was used to provide a global picture of cognitive status and dementia severity. Participants' MMSE scores ranged from 9 to 25 (mean = 20.4, SD = 6.54). Four of the participants' scores fell into the

‘mild’ dementia bracket and the remaining participant scored 9, placing her in the ‘severe’ dementia bracket.

Family caregivers

The main family caregivers (N=5; 4 males) of the participants with dementia also consented to take part in the study. Four of the caregiver participants were spouses and one was the son of the person with dementia. These participants ranged from 62 to 79 years of age (Mean = 72.2, SD = 7.52). Caregivers were also asked to complete the Mini Mental State Examination in order to rule out any cognitive impairment on their part. Scores ranged from 26 to 30 (Mean = 28, SD = 1.58).

5.2.1.1. Ethical approval

Ethical approval for this study was gained under that granted to the Computer Interactive Reminiscence and Conversation Aid (CIRCA) Project.

5.2.1.2. Ethical procedure

Letters were sent out to people with dementia and their families at a local daycare centre informing them of the study and asking if they were agreeable to being approached to take part. On receipt of agreement to be approached the study was explained again to individuals with dementia and their family members and they were then asked again if they would like to take part. If they were agreeable they were asked to give either written or verbal consent that was witnessed by a neutral third party.

All participants were informed that they were free to stop proceedings at any time. However, given the memory difficulties of people with dementia their

continued consent was checked at regular intervals. If the participant appeared to become uncomfortable or distressed at any point, the session was ceased whether or not he/she expressly requested to stop.

5.2.2. Materials

Caregiver participants were asked to select six photographs from their family albums that they considered to have personal relevance for their relative with dementia. The carers were then asked to choose three black and white and three colour photographs from as diverse a time span as they liked in order to achieve as wide a range of stimuli as possible. Carers were not required to select only images of themselves or the person with dementia, but were encouraged to also incorporate images of significant places/events/family members/pets and friends, etc. if they so wished. However, all photographs selected by the caregivers contained people. All of the selected images were scanned into a Sony laptop computer for viewing. All sessions were video recorded using a Sony Mini DV Video camera.

5.2.3. Procedure

The study was conducted in the personal homes of each family in order to make the participants as comfortable and relaxed as possible within their surroundings. Each participant sat at a table with the investigator in an unoccupied room in their house. A video camera was set up in the corner of the room to record the session. The investigator explained the process again and all participants agreed to be video recorded.

Week 1 - Individual Condition 1: Caregiver

Caregiver participants were asked to identify significant details about each photograph such as names and locations and were then invited to reminisce in response to each one in turn with the investigator (Individual Condition 1). Caregivers were encouraged to talk about each image for as long as they wanted. Each caregiver's reminiscence session was then transcribed verbatim and significant names, dates, locations and other identifying information about each photograph was noted.

Week 2 - Individual Condition 2: person with dementia

A week later, participants with dementia were invited to complete the same procedure with the investigator. All of the people with dementia's reminiscence sessions were recorded and then transcribed verbatim and significant names, dates, locations and other identifying information were again noted. The responses of people with dementia and their family members between the Individual and Dyadic Conditions were then analysed.

Week 3 - Dyadic Condition: Caregiver and person with dementia

One week later, each caregiver and person with dementia were invited to repeat the procedure together in the presence of the investigator. The caregivers were encouraged to allow the person with dementia to take the lead in the session and to offer help only if they thought their relative needed it. All sessions were video recorded using a Sony Mini DV Video camera, for the purposes of verbal and non-verbal behavioural coding. All sessions were again transcribed verbatim.

5.2.4. Coding of verbal responses

All of the participants' verbal output was coded using the conversational coding categories and operational definitions shown below in Table 5.1.

Table 5.1. Conversational coding categories and their operational definitions.

Category	**Operational Definitions**
Identification of a person	Number of times the carer/person with dementia correctly identifies a person in the photograph.
Identification of a place	Number of times the carer/person with dementia correctly identifies a place in the photograph.
Story-telling	Number of times the carer/person with dementia tells a story, i.e. a combination of three or more utterances that *narrates* a general or specific single or recurring situation or event from the person's own experience. Either seemingly related *or* unrelated to the stimulus topic
Non-factual information	Number of non-factual information units provided by the person with dementia that are previously or subsequently verified as such by the caregiver. For example, an information unit would be considered to be non-factual if a person with dementia identifies someone in a photograph as his daughter whilst his caregiver has either already identified the person as someone else in the Individual Condition or if she does the same in the Dyadic Condition.
Unknown	Number of times either partner is unable to name or is unsure of a significant person or place/event depicted in the photograph.

These categories were selected in an attempt to represent the type of information that might be provided about the photographs. For example, a photograph of their daughter's wedding could have a wealth of information attached to it such as the name of the bride and groom, the location of the wedding, the year and month it occurred and perhaps a story about something unusual that happened on the day.

Personal Detractors

As described in Chapter 2, section 4.5, personal detractors are instances of caregiver behaviour that detract from the personhood of the person with dementia. In this study all instances of caregivers creating Personal Detractors towards people with dementia were recorded. Both verbal and non-verbal variants were included within this category. For example, if the caregiver looked at the interviewer and shook his head in response to something the person with dementia said this would be coded as 'ignoring'. An example of a verbal Personal Detractor would be if the caregiver shouted at the person with dementia, which would be coded as 'intimidation'.

5.2.5. Interrater reliability

Personal Detractors

Videotapes of the interactions were viewed and coded independently by two raters for instances and category of verbal and nonverbal Personal Detractors. Agreement between the raters was 100%

5.2.6. Data analysis

Non-parametric analyses using Wilcoxon Signed Ranks test (related samples) were used to analyse the verbal output of people with dementia and their caregivers pertaining to the variables listed in Tables 5.2. and 5.3. in both the Individual and Dyadic Conditions. The existence of Personal Detractors was also analysed between conditions.

5.3. Results

5.3.1. Describing the photographs

People with Dementia

Table 5.2 contains the mean numbers of correct identifications of people, correct identifications of places, stories told, unknown and non-factual information produced by people with dementia across the Individual and Dyadic Conditions. Comparison of the amount of information produced using Wilcoxon signed ranks test indicated that there were no significant differences in the amount or type of information produced by people with dementia in the individual and dyadic conditions (both $p>0.05$). In other words, there was no change in the amount of information that people with dementia were able to produce in response to the images regardless of who their interaction partner/s was/were.

Table 5.2. Mean, standard deviation (SD) and range of responses produced by people with dementia within the Individual and Dyadic Conditions

Condition	**Identification Person**			**Identification Place**			**Stories**			**Unknown**			**Non-factual**		
	M	SD	R	M	S	R	M	S	R	M	S	R	M	S	R
Individual	9.4	3.13	6-14	1	1	0-2	1.4	1.94	0-4	5.6	2.30	3-8	4.2	2.94	2-9
Dyadic	9.2	5.58	4-17	1.2	0.83	0-2	0.6	0.89	0-2	5.4	1.14	4-7	4.2	2.68	1-7

Caregivers

The mean numbers of identifications of people, identifications of places, stories told and unknown information produced by caregivers within the Individual and Dyadic Conditions are shown in Table 5.3. Comparison between the two conditions using Wilcoxon signed ranks test revealed that the caregivers identified significantly fewer people ($z = -2.02$; $p<.05$) and places ($z = -2.07$; $p<.05$) in the Dyadic Condition. In other words, caregivers behaved differently when they reminisced with their loved-ones with dementia. All other differences in caregiver responses within the Individual and Dyadic Conditions (identification of people and places; story-telling and unknown information) were non-significant.

Table 5.3. Mean, standard deviation (SD) and range of responses produced by caregivers within the Individual and Dyadic Conditions.

Condition	**Identification Person**			**Identification Place**			**Stories**			**Unknown**		
	M	SD	R	M	SD	R	M	SD	R	M	SD	R
Individual	14.8	4.14	8-18	3.8	2.38	2-8	3.4	3.13	0-	2.4	2.07	0-5
Dyadic	*7.8	3.42	4-13	*2	2.91	0-7	1.4	1.67	0-	0.8	0.44	0-1

*$p<0.05$.

The following transcript excerpts provide examples of the coding categories from both people with dementia and their caregivers.

Examples of the identification of a person

Caregiver no. 1 – Photograph of daughter's wedding.

Investigator: *"Can you tell me who's in this picture?"*

Caregiver: "That's my two daughters."

I: *"Mhhm."*

C: "And my son in law and his brother."

I: *"Mhhm. What's the names there?"*

C: "Mary, Lucy, Dean and Derek."

Person with dementia no. 1 (Severe Dementia) - Photograph as above.

Person with dementia: Oh aye. That's Duncan's brother."

I: *"Mhhm."*

P: "No, that's Dean's brother."

I: *"Mhhm."*

P: "Dean and Derek."

I: *"Mhhm."*

P: "That's er my lassie. What do you call her? Lucy."

I: *"Mhhm."*

P: "And Mary?"

The above examples illustrate that the person with dementia provided almost exactly the same information about the people in the photograph as his caregiver did. However, the caregiver went into greater detail about how they were

related to her. The person with dementia showed that he knew who they were by providing the correct names for all the individuals depicted.

Examples of the identification of a place

Caregiver no. 5 – Photograph of the person with dementia in the R.A.F.

Investigator: *"Can you tell me who's in that picture?"*

Caregiver: "That's Richard."

I: *"Mhhm."*

C: "That's at Christmas. He sent that picture to his mother."

I: *"OK."*

C: "From er, the Middle East."

I: *"Mhhm."*

Person with dementia responding to the same photograph:

Person with dementia no. 5 – (Mild Dementia) Photograph as above.

Investigator: *"Can you tell me who's in that picture?"*

P: "Here, he's no a bad looking bloke, is he, eh?"

I: *"I know!"*

P: "Cor blimey, it's me!" (Both laugh) (Reading from the back of the photo) "Mother".

I: *"Mhhm."*

P: "That, I think was taken during the war."

I: *"Mhhm."*

P: "Judging by, er, my dress."

I: *"Mhhm."*

P: "I think that it would probably be taken, er, overseas."

I: "Uh-huh."

P: "Middle East. Uhm, that's about all that er, is there anything else that I should bring up?"

These examples illustrate that both the caregiver and the person with dementia were able to identify where the photograph was taken. However, of interest here is that neither of them provided any more specific details about the location than the other.

Examples of story-telling

Caregiver no. 4 – Photograph of his wedding day.

Caregiver: "That's myself and (spouse's name) obviously."

Investigator: "Uh-huh."

C: "On our wedding day."

I: "Mhhm."

C: "That was fifty four years ago now."

I: "Gee whiz!"

C: "And er, as a matter of fact, I was in the floristry trade. I was a manager at the time."

I: "Mhhm."

C: "And we had er, we got a room in the (hotel name). And I had to supply the flowers."

I: "Right."

C: "Yeah."

I: *"Oh!"*

C: "And we were married in (Name) Church and that – (spouse's name) was a member of that, the big church."

I: *"Mhhm."*

This story serves as an example of the types of stories that caregivers told during the study. Many of these stories were rich in detail and clearly very significant to the caregivers. The stories told by caregivers were very focused on the scenarios depicted in the images and very rarely strayed from those. In contrast the people with dementia often told stories unrelated to the specific photograph. For example:

Person with dementia no.4 – (Mild Dementia) Photograph of her daughter and grandchildren

Person with dementia: "Oh, that's my daughter."

I: *"Uh-huh."*

P: "And the other one. But, and that's a wee boy that we did, thought we weren't getting."

I: *"Oh, right I see!"*

P: "You see? It was all girls, girls, well it was all boys when I was the only girl that was born when to my mother."

I: *"Uh-huh, uh-huh"*

P: "And that and it was all boys she had.

I: *"Uh-huh."*

P: "And er, that was it and then this after well there was two of them died."

I: "Mhhm."

P: "Quite early in their life."

The above example of story-telling is representative of the types of stories told by participants with dementia. Although the image clearly triggered a memory in the person with dementia, the story itself is not obviously related to the photograph itself or the event depicted in it. Additionally, the people with dementia sometimes recognised the photographs as being personal but offered incorrect information in response to them:

Example of non-factual information

Person with dementia no. 3 (Mild Dementia) – Photograph of his wedding day.

Investigator: "*OK. Can you tell me who's in that picture?"*

Person with dementia: "That's me, *my daughter*…"

I: "Mhhm."

P: "My wife and I think that was my *grandson.*"

In this example the participant misidentified two of the individuals in the image as his daughter and grandson. Caregivers themselves were not always able to name significant places and people in the photographs in the Individual Condition, for example:

Caregiver no. 3 – Photograph of her granddaughter's wedding day.

Investigator: "Can you tell me who's in that picture?"

Caregiver: "That's our adopted granddaughter."

I: *"Mhhm."*

C: "And her husband."

I: *"OK."*

C: "Don't ask me his name, 'cause I don't know it."

I: *"OK"* (both laugh).

However, this occurred only twice in the Dyadic Condition, in comparison to 9 times in the Individual Condition.

In summary, the behaviour of people with dementia did not differ between the Individual and Dyadic Conditions in conversational terms. However, caregivers produced less information in response to the photographs in the Dyadic than in the Individual Condition.

Table 5.4. Personal Detractors

Personal detractor	Number	Mean	SD
Outpacing	16	3.2	1.92
Ignoring	14	2.6	5.27
Disparagement	11	2.2	2.48
Infantilisation	4	1.4	1.67
Mockery	5	3.2	1.92
Disruption	2	0.4	0.54
Imposition	2	0.4	0.54
Total	56	11.2	7.49

However, the findings further highlighted the non-existence of Personal Detractors in the Individual Condition and a total of 56 in the Dyadic Condition (Table 5.4). Seven of the 17 categories of personal detractors described by Kitwood (1997) were identified both verbally and non-verbally in the transcripts and videotapes. Figure 5.1. depicts the proportion of occurrence of each of the seven types of personal detractor.

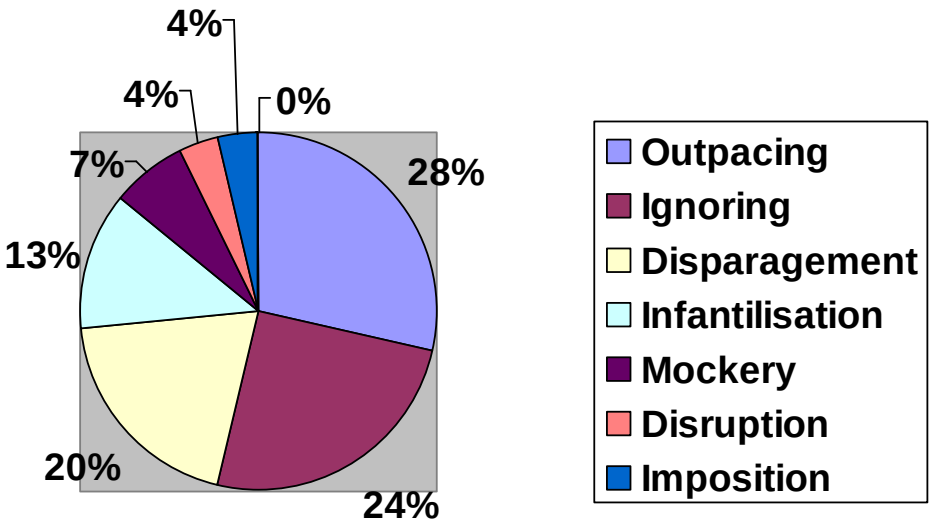


Figure 5.1. Percentage of each type of personal detractor

Outpacing was the personal detractor that occurred most often (16 times in total) in the Dyadic interactions. The prevalence of this personal detractor in this study indicates that caregiver frustrations with interacting with their relatives with dementia are most often prompted by impatience. More specifically, this irritation indicates that caregivers expected their loved ones with dementia to be able to respond within a particular time frame. If they failed to do so, caregivers tended to rush their relatives to answer, which did not facilitate the person with dementia in any way. If anything, this increased the pressure on people with dementia.

Ignoring was the second most common personal detractor, occurring 14 times in total in the Dyadic interactions. The pervasiveness of this personal detractor indicates the caregivers' perception of their relative with dementia's lack of awareness of their social surroundings. For example, one caregiver repeatedly leaned behind his wife to look over at the investigator and whisper to or make exaggerated faces at her during the Dyadic Condition. Presumably, the caregiver did not wish his wife to know he was doing this, hence his furtive behaviour. However, there was no reason why his wife would not have seen or heard him do this as he was sitting very close to her.

Other examples of ignoring occurred which were even more obvious to the person with dementia. For example, the wife of a person with dementia directly asked him where she (his wife) was in the room. When he pointed to her and said "There!" She turned to the investigator and said "'Cause sometimes he doesn't think that." This is a striking example of 'ignoring' as it suggests that the caregiver either assumes that her husband is unable to understand her comment to the investigator or that she does not see it as an undermining action on her part to talk about his 'failings' in his presence.

Disparagement occurred 11 times in total in the Dyadic Condition. This most often took the form of the caregiver abruptly correcting the person with dementia when he/she made a mistake in identifying a person, place or situation in a photograph. This personal detractor highlights that the caregiver *wanted* his/her relative with dementia to be able to get things right. However, his/her response to the person's mistake revealed the caregiver's expectations that the person with dementia *should* be able to identify certain strategies correctly.

Infantilisation occurred 4 times in total in the Dyadic Condition. The appearance of this personal detractor suggested a benign facilitative instinct on the part of the caregivers towards their relatives with dementia. However, talking to an adult as one might to a child indicates an underlying negative attitude towards people with dementia with regard to their abilities and reality.

Mockery also occurred 4 times in total, comprising a caregiver imitating his mother with dementia, two instances of caregivers laughing at something the person with dementia said and one looking over at the investigator. The following transcript example indicates how an innocent attempt to make a joke undermined the conversational status of a person with dementia:

Husband: "This guy's your favourite."

Person with dementia: "Oh, I know. I always got on well with him."

H: "Come on. What is it? I'm being sarcastic when I say that."

P: "Don't be so flamin' cheeky!"

H: " No, I'm being sarcastic when you, come on. Who is that?"

P: "That was er…"

H: "Come on!"

In this example the caregiver seemed to be trying to prompt his wife to name the man in the photograph by sarcastically alluding to the fact that she did not like him. However, it is most likely that his wife did not recognise the man in the photograph and agreed with her husband's initial comment about him being her favourite in order to mask her uncertainty. As such, her husband's admission that he was being sarcastic damaged her attempt to save face.

Disruption and imposition both occurred twice occurred twice in total. Disruption involved the person with dementia being interrupted by the caregiver. The appearance of 'disruption' in the Dyadic Condition suggested either a level of impatience on the part of the caregiver or a disregard for the person with dementia's input. Imposition involved caregivers taking hold of the person with dementia's hand and placing it somewhere else. The incidence of 'imposition' in the Dyadic Condition indicates caregivers' expectations of their relatives' inability to complete an action.

Caregivers also indicated their expectations of their loved ones with dementia in other ways by suggesting that they should be able to recognise significant people, places and events represented by the photographs. This is typified by the following example of a married couple discussing their wedding photograph.

Person with dementia: "That's Daisy."

Caregiver: "Mhhm."

P: "And Leonard and Marnie."

C: "No! That's, how can that be Marnie? Come on! It's your sister."

P: "Ah, Meg?"

C: "No, Maria."

P: "Maria."

People with dementia also indicated their own expectations with regards to their ability to recognise people and situations depicted in the photographs. The following example directly illustrates the feelings experienced by one participant with dementia on looking at a one of his holiday photographs.

Investigator: *"Can you tell me who's in that picture?"*

Person with dementia: "Can I tell you who's in that picture? That's (spouse's name) and I."

I: *"Mhhm."*

P: "That's all."

I: *"OK."*

P: "I don't know any of the rest, I should know their faces but I don't."

This person clearly indicated that he thought he *should* have been able to recognise the people in the photograph other than himself and his wife. Closer examination of the transcript revealed that he was also unable to identify the location and events in the photograph. However, in the Dyadic Condition his wife addressed this sensitively and helped him in the following way.

Wife: "In your favourite place in Spain. Where, what?"

Person with dementia: "Eh?"

W: "Your favourite place in Spain. Beginning with a…"

P: "Where about where we in Spain?"

W: "Well, your favourite place, beginning with a 'B'."

P: "Barcelona."

W: "That's it. That's it."

At times people with dementia failed to recognise themselves, their children and other very close relatives in the images. This example is taken from a caregiver's

transcript from the Individual Condition that illustrates her feelings of upset when her husband forgets about the death of their daughter.

Wife: "That's (her daughter's name)."

Investigator: "(Her daughter's name)."

W: "Dad's girl."

I: "(Laughs) OK."

W: "He keeps asking me where she is. He says, she's never been to visit me. I get, I get hurt."

In this instance the caregiver appears to believe that her husband is denying his daughter's death. Presumably this event was very upsetting for the entire family and particularly devastating for the caregiver and her husband as parents. As such, it was not so much their relationship with their daughter that the caregiver felt was negated; rather she was referring to their shared and very painful experience of her death has been forgotten by her husband. Consequently, the caregiver has to experience this loss alone and is hurt by this.

5.4. Discussion

The findings of this study have implications for the way that reminiscence activities are conducted with individuals with dementia. For example, the use of family photographs in the presence of a family member was complicated by mutual expectations of what 'should' be remembered and discussed. As such, caregiver training on the sensitive use of personal photographs in reminiscence could be of benefit.

Research question 1 asks "Will the presence of family caregivers influence how their loved ones with dementia respond to the photographs? If so, in what way does this manifest?" Results indicated that people with dementia did not behave differently between the Individual and Dyadic Conditions with regards to the amount of information they produced. Research question 2 asks "Will the presence of relatives with dementia influence how their family caregivers respond to the photographs? If so, in what way does this manifest?" Caregivers produced more factual information about the contents of the photographs in the Individual than in the Dyadic condition. Although the difference was non-significant, the finding that caregivers also forgot information but that this occurred less in the dyadic than in the individual condition is a rather ambiguous finding that suggests two main explanations. Firstly, caregivers might not have wished to appear less knowledgeable in the presence of their relative with dementia. If this is the case, then their face-saving tactics are comparable to those employed by their relative with dementia. However, the data indicates that two of the caregivers *did* admit to being unable to name certain identifying elements of the images. This finding therefore suggests that the caregivers may have merely been following the investigator's instructions by allowing their relative with dementia to take the lead.

Caregivers also created personal detractors in response to their loved ones with dementia which may have owed to the impact of their prior relationships. People with dementia clearly had expectations about what they should be able to remember. Caregivers indicated their own expectations that their loved ones should be able to recognise particular people or places in the photographs. Their use of personal detractors indicated this and also their low expectations of what their relatives with dementia 'should' be able to do.

5.5. The Relevance of this Study to the 'Collaborative Personhood Model'

As a whole, these findings suggest that caregivers could benefit from training and education on the effects of dementia and on helpful approaches to communication. A more collaborative approach would benefit both caregivers and people with dementia by enabling significantly more satisfactory interactions. Educating caregivers could shift their focus away from eliciting 'correct' answers or the production of 'relevant' memories. Instead, the emphasis should be placed on enjoying a shared experience and in maximising the retained skills of the person with dementia. For example, if a person with dementia misinterprets the contents of an image her caregiver could suggest what the photograph might represent rather than correcting her. Such a facilitative and encouraging approach to communication might benefit the relationship as well as maintaining the personhood of the individual with dementia rather than undermining her.

Clearly, the participants with dementia in the current study retained a significant amount of recognisable and functional speech. As such, language was their main mode of communication and as such was the most obvious route to reach them. However, for those people at later stages of the illness whose speech is failing, collaborative communication becomes more complex for the advantaged interaction partner. The following chapter explores a range of collaborative communication techniques with an individual with severe dementia with little recognisable speech.

CHAPTER SIX

STUDY 3 - COMMUNICATION AND AWARENESS OF SELF IN SEVERE DEMENTIA

6.1. Introduction

The previous two studies have highlighted the social nature of self-image and the importance of the behaviour of the interaction partner for people with mild to severe dementia. The next study examines the impact of severe speech disturbance on communication and self-awareness in Jessie, a lady whose dementia has reached an severe stage. The study comprises two parts that together provide further insight into the impact of both severe dementia and the environment, particularly the behaviour of interaction partners, on communication and the presentation of self.

The first part examines Jessie's spontaneous verbal and nonverbal behaviour, including imitation, eye contact and turn taking to explore the impact of severe dementia on communication and the awareness of self. The 'Still Face' paradigm is used to explicitly examine the impact of Jessie's severe dementia on the urge to communicate and awareness of self and other. As in the previous two studies the role of the interaction partner is also examined. In particular this study looks at the use of imitative behaviour as a means of keeping the interaction going and the occurrence of contingent behaviours. The second part uses observation over a five-day period to explore the impact of the environment in which Jessie lives on her day-to-day opportunities for engagement and social interaction with caregivers and other people with dementia.

6.2. Part 1 - The urge to communicate

As dementia severity progresses people become reliant on caregivers to initiate engagement and occupation as well as all activities of daily living. This dependency is commonly interpreted as signifying that not only do people with AD have nothing to contribute to the social world but that they have actually lost the urge to communicate and participate in social interactions. Given that we are apparently born with this urge (Meltzoff & Moore, 1983) and it is part of our adaptive human repertoire, the notion that the urge to communicate can be lost is clearly a serious claim.

The 'Still Face' paradigm (Tronick, Als, Adamson, Wise, & Brazelton, 1978) has developed as an approach to exploring the communication urge in a wide range of populations. The 'Still Face' is a deliberate manipulation of the social situation where the communication partner disengages in the middle of an interaction, avoids eye contact and does not respond to their partner for a period of time (Tronick, et al., 1978). Using the 'Still Face' with children with autistic spectrum disorder, Nadel et al. (2000) found that they made deliberate attempts to interact with her, for example standing in front of her, looking into her eyes and touching her, during the disengagement phase. This violated the commonly asserted beliefs that people with autistic spectrum disorder, who are typically described as socially isolated, lack the drive or urge to engage in social interactions with others (Hobson, 1993).

The behaviour of the children in Nadel's study parallels the efforts of babies of depressed mothers who make attempts to re-engage in social interaction when the mother stops interacting with them (Tronick & Weinberg, 1997). These infants experience intermittent responsiveness from their mothers that leads to them making frequent visual checks of their mother's faces for signs of renewed interaction. If the

mother fails to make a response for a prolonged period, the infant disengages and shows signs of anxiety. Effectively depressed mothers present a naturalistic 'Still Face' and their infants' responses indicate that their social expectancies have been violated. Nadel et al. (2000) judged that the attempts made by children with autistic spectrum disorder to gain her attention were evidence that they too have social expectancies that the 'Still Face' violates.

These findings from autistic spectrum disorder have potential application to AD, where people become socially isolated and excluded through increased dementia severity. Whilst there are clear differences between autistic spectrum disorder (a developmental disorder) and AD (a neurodegenerative disorder), both populations are viewed by others as non-participants in the social world. As speech becomes increasingly inefficient as a communication tool people at the later stages of dementia have difficulty in expressing themselves, which is often interpreted by caregivers as lack awareness of self, of their surroundings and of social norms. This proposed similarity to individuals with autistic spectrum disorder merits the application of the 'Still Face' paradigm to explore the urge to communicate in severe dementia.

A key element in Nadel et als' (2000) studies with children with autistic spectrum disorder is the use of imitation. Nadel et al. (2000) argued that mirroring the actions of individuals with autistic spectrum disorder provided them with the opportunity to lead and set the pace of interactions. Such work can be seen as going back to the basics of communication. Parents of newborns typically repeat and reinforce the facial expressions, sounds and movements made by their infants. This imitation forms the basis of their early interactions and provides the foundation for future communication. In parent-infant interactions this reciprocal behaviour arises quite naturally and is both spontaneous and unselfconscious (Tomasello, 1992). These

nonverbal behaviours continue to play a role into adulthood in maintaining social interactions and important conversational activities such as turn-taking (Sacks, Schegloff & Jefferson, 1974), and as demonstrated in the first two studies, are still apparent in people with dementia, at least up until the severe stage of disease progression.

6.2.1. Study aims

This study aims to examine the proposal that as dementia severity progress, there comes a point where people no longer have the urge to communicate and engage in social interaction. Put another way, it examines the idea that with severe dementia severity, people become isolated, or perhaps, separated from the social world into a world of their own. The 'Still Face' paradigm is used as a means of investigating the impact of severe dementia on communication behaviour and social expectancies. The study will also afford some further insight into the relationship between speech and presentation of self, by providing the opportunity, through provision of an interaction situation, for Jessie to demonstrate awareness of self and other.

Research questions:

1. Will the 'Still Face' reveal that Jessie retains the urge to communicate?
2. If so, what behaviours will signify this?
3. Will the 'Still Face' reveal that Jessie retains a sense of self awareness?
4. If so, what behaviours will signify this?
5. How can the interaction partner facilitate communication with Jessie?

6.2.2. Method

6.2.2.1 Participant

Jessie is a 79-year old lady who has lived in a nursing home for the past 3 years. She was diagnosed with dementia 4 years ago. Jessie meets the NINCDS-ADRDA criteria for probable AD (McKhann et al., 1983). At the time of the study Jessie was suffering from severe dementia and it was not possible to conduct a Mini Mental State Examination (MMSE: Folstein, Folstein & McHugh, 1975) or any other formal assessment.

6.2.2.2. Ethical approval

Ethical approval for this study was gained under that granted to the Computer Interactive Reminiscence and Conversation Aid (CIRCA) Project (DATE, REF NO,). See Appendix I for approval letter.

6.2.2.3. Ethical procedure

A two-part consent procedure was used to carry out this study. First Jessie's sister was contacted and the study explained to her. She agreed to Jessie being asked to take part. On the first day of the study Jessie was approached by the investigator and was asked if she would like to come and have a chat in one of the sitting rooms. She was told that the session would be filmed and that she was free to leave at any time. A neutral third party witnessed that Jessie gave verbal consent. This process was repeated before the start of session 2. Jessie was frequently asked if she wanted to continue or finish. Continual consent helped ensure that Jessie only continued if she so wanted.

6.2.2.4. Procedure

Session 1

Jessie and the investigator sat at a table, with Jessie's chair up to the table and the investigator sitting to her right, not directly facing each other. The investigator started a conversation and deliberately but spontaneously imitated some of Jessie's nonverbal behaviours and language. The session was recorded on a video camera, positioned to capture both participants in the interaction.

Session 2 (2 days after Session 1)

Jessie and the investigator sat side by side at a table with their chairs turned towards each other, but not directly facing. The investigator initiated a conversation and the Session was recorded on video.

Within this session two conditions were used:

Condition 1: Deliberate Imitation. The investigator attempted to imitate all of Jessie's nonverbal behaviours.

Condition 2: Still Face. The investigator adopted the 'Still Face' at intervals during the interaction.

Condition 1 ran throughout the session, except for the time when Condition 2 was running. Condition 2 occurred seven times during the session at irregular intervals and each 'Still Face' period was stopped when Jessie tried to leave or showed any sign of agitation.

Session 1 lasted for 23 minutes and Session 2 for 35 minutes.

6.2.3. Behavioural Coding

Ten minutes in the middle of each session were coded to allow for the difference in duration between the two Sessions and to gain an impression of the interactions in full flow. Therefore, Session 1 (23 minutes) was coded from 6.5 minutes into the interaction for 10 minutes, leaving 6.5 uncoded minutes at the end of the interaction. In Session 2 the occurrence of the 'Still Face' periods meant that there was no single 10-minute period to code. From this session five 1-minute periods before and five 1-minute periods after the 'Still Face' were coded.

The communicative output of Jessie and the investigator was coded during both sessions using the following categories and operational definitions (Table 6.1):

Table 6.1. Coding categories and their operational definitions for both partners' interaction turns.

Event coding		**Operational definitions**
Turn-taking*	Verbal	Communicative turn using speech *or* communicative sounds such as 'ahem'/ 'uh-huh'
	Non-verbal	Communicative turn using non-verbal behaviours such as nodding/shaking head or shrugging shoulders
Emotion	Neutral	No emotional behaviour
	Happy	Laughing or smiling
	Sad	Speaking in an upset tone or crying
	Other	Any other emotional behaviour (e.g. shouting, fretting).
Imitation		Jessie imitates investigator (non-verbal)
		investigator imitates Jessie (non-verbal)
		Jessie imitates investigator (verbal)
		investigator imitates Jessie (verbal)
Eye gaze	Partner	Direct eye contact with partner
	Close	Looking at partner but not direct eye contact
	Ahead	Looking straight ahead

	Elsewhere	Looking anywhere else

* In cases where both verbal and non-verbal behaviours were observed in a single communication turn, verbal behaviour was coded as the dominant behaviour as Jessie had retained a reasonable amount of speech.

6.3. Results

To understand the impact of severe dementia on communication the categories of verbal and nonverbal behaviours were examined separately. For each type of behaviour Jessie was considered as part of a dyad.

6.3.1. Turn-taking

Although Session 1 comprised more turns than Session 2 (265 & 229 respectively), they were relatively equally distributed between the dyad in both (Session 1 Jessie 127 turns, me 138; Session 2 Jessie 114, me 115). Jessie reciprocated all her partner's turns in Session 2 and failed to respond to only 11 turns in Session 1. By contrast all of Jessie's turns were reciprocated by I in both sessions. Whilst there were a few more nonverbal turns in Session 2 than Session 1, by far the majority of contributions by both participants were verbal.

6.3.2. Emotion

Jessie's emotional state was neutral in both Sessions for most of the time (79.66% and 83.83% respectively). She spent 15.83% of the time in a happy emotional state in Session 1 and 16.16% of the time in Session 2. By contrast, the investigator was happy for the majority of both Sessions (69.66% & 73.33% respectively) and in a neutral emotional state for much less of the time (28.66% &

26.66% of the time respectively). Neither Jessie nor her interaction partner showed any signs of sadness in either session and there was only one occurrence of any other emotional behaviour on the part of Jessie or the investigator (4% & 1.5% of the time respectively), which occurred in Session 1.

6.3.3. Imitation

Both Jessie and the investigator engaged in imitative behaviour in both sessions (Table 6.2). Spontaneous imitation by Jessie is much more likely to be verbal than nonverbal although the amount of both drops in Session 2. When the investigator imitated Jessie spontaneously i.e. when she deliberately imitated some of Jessie's nonverbal behaviours and language (Session 1), much more verbal than nonverbal imitation occurred. In Session 2 where the investigator deliberately imitated Jessie's nonverbal behaviour, there was still more verbal imitation, although the amount of nonverbal does increase.

Table 6.2: Occurrence of imitation over Sessions 1 and 2.

Type of imitation	**Total imitative behaviours**			
	Session 1		Session 2	
	Jessie	Investigator	Jessie	Investigator
Verbal	17	33	7	18
Non-verbal	2	8	0	14
Totals	19	41	7	32

6.3.4. ‘Still Face’

Jessie’s behaviour across the seven ‘Still Face’ periods was examined for eye gaze, proximity and emotion as well as other behaviours that occurred in place of turn taking (Table 6.3). Of the 13 instances recorded, six are Jessie speaking to the investigator, 3 are moving closer, 3 are preparing to leave the room and one is an emotional display of anxiety or agitation. On the three occasions when Jessie stood up to leave, the investigator stopped the ‘Still Face’ and resumed speaking to Jessie. In some ‘Still Face’ periods (2, 3 and 7) Jessie makes more than one attempt to re-establish contact with the investigator.

Table 6.3. Jessie’s eye gaze and accompanying behaviours during the ‘Still Face’ periods.

‘Still Face’ number	**Duration (secs)**	**Time behaviour occurred (secs)**	**Direction of gaze**	**Accompanying behaviours**
1	23	21-23	Investigator	Jessie stands up to leave
2	42	02-04	Investigator	Jessie pulls her chair closer to investigator
		12-15	Investigator	Jessie attempts to talk to investigator
3	43	15-29	Elsewhere	Jessie pulls her chair closer to investigator
				Jessie attempts to talk to investigator
		39-43	Investigator	Jessie attempts to talk to investigator
4	28	27-28	Investigator	Jessie attempts to talk to investigator

5	20	18-20	Ahead	Jessie stands up to leave
6	54	53-54	Investigator	Jessie attempts to talk to investigator
7	22	7-20	Elsewhere	Jessie pulls her chair closer to investigator Jessie breathes heavily
		20-22	Investigator	Jessie attempts to talk to investigator Jessie stands up to leave

To understand the impact of the 'Still Face' on Jessie, her eye gaze during these periods was compared with Sessions 1 and 2 (Figure 6.1.). In the 'Still Face' periods Jessie spent much more time looking elsewhere in the room than in Sessions 1 and 2.

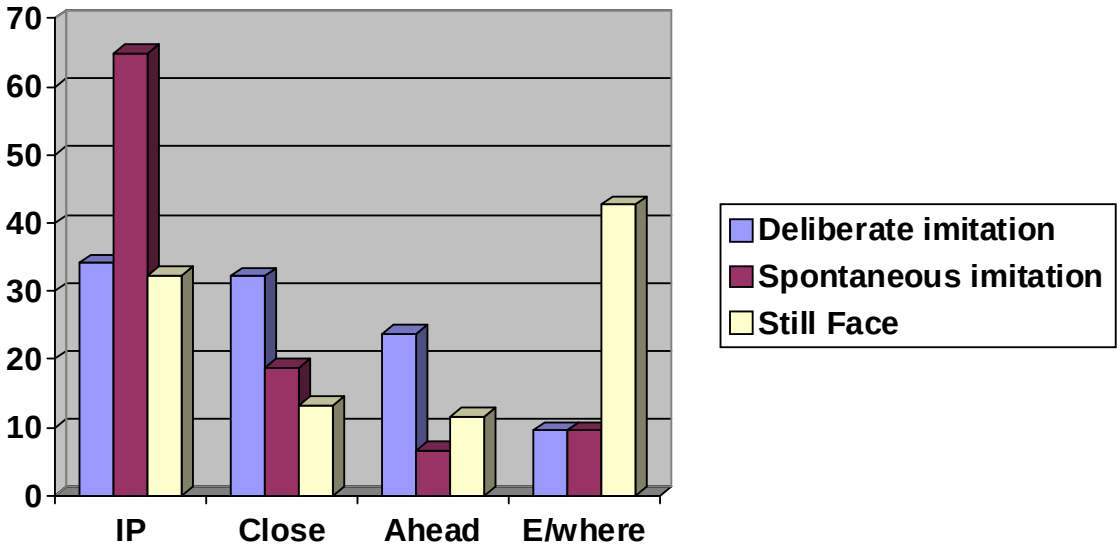


Figure 6.1 Direction and proportion (%) of eye gaze during Sessions 1 and 2 and 'Still Face'.

Jessie looking directly at the investigator dropped back to the level in Session 1 during the 'Still Face' periods. However, it was notably for more frequent, shorter periods than in either Session 1 or 2.

6.4. Discussion

Jessie clearly demonstrated the urge to communicate and participate in social interactions. Her repertoire contained many communication behaviours that can be used as the basis of successful social interaction. Verbally, Jessie spoke throughout the sessions, although her speech was often indistinct and the contents of what she said were typically hard to follow. Nonverbally, Jessie made a lot of eye contact during the interactions, although nowhere near as much as the investigator. She also spent quite a lot of time looking nearby, but not directly at, the investigator, particularly in Session 1. It is possible that this is an indication of discomfort as has previously been suggested in autistic spectrum disorder where direct eye contact is described as 'too painful' (Caldwell, 1998).

Jessie's turn-taking ability was well preserved and served to regulate the flow of interaction. She typically reciprocated verbally to the investigator's turns but also used nonverbal responses, such as nodding her head, to keep the interaction going. Both Jessie's turn taking and eye gaze appeared to be influenced by the seating positions as indicated by the proximity data. Specifically, there was less non-reciprocation and more direct eye gaze in Session 2, when Jessie and the investigator were sitting on the same side of a table. Emotional behaviour, however, did not appear to be affected by this. Aside from one instance in Session 1 where Jessie demonstrated concern that her hands were sore, most emotional behaviour consisted of smiling and laughing, i.e. 'happy' behaviour.

In both Sessions, the investigator showed high levels of 'happy' behaviour (69% and 73% Session 1 and Session 2 respectively). In part this can be attributed to the role of smiling and laughing as interaction-maintenance activities, alongside nodding and encouraging verbal behaviours such as "ahem", "right", and "I see". The investigator also appeared to be using eye gaze as an interaction-maintenance activity with very high levels of direct eye contact (94% and 99% Session 1 and Session 2 respectively).

Imitation was used by both Jessie and the investigator in both Sessions, but more so by the investigator. Verbal imitation was used spontaneously by both partners and predominated, even when the investigator was deliberately imitating Jessie's nonverbal behaviours. This suggests that where both parties in an interaction are verbal, then imitation of verbal behaviour is a naturally occurring supportive behaviour.

In the 'Still Face' situation Jessie made several verbal and non-verbal attempts to interact with the investigator such as moving her chair in closer and speaking to the investigator. These attempts to engage the investigator and resume the interaction are reminiscent of the responses of children with autistic spectrum disorder reported by Nadel et al. (2000). As such Jessie's actions suggest that her social expectations were violated by the 'Still Face' situation and this was uncomfortable for her.

Jessie's discomfort during the 'Still Face' was apparent from her getting up from her chair and one instance when she started to breathe heavily. There was also a huge increase in the amount of time she spent looking away from the investigator relative to the non-'Still Face' periods. This was punctuated by frequent, very short glances at the investigator's eyes, which could be interpreted as checking for eye contact to signal the resumption of the interaction. These behaviours did not occur

outside of the ‘Still Face’ parts of Session 2 and provide strong evidence of Jessie’s continuing desire to participate in social interactions and her response to the violation of expected interaction behaviour. Furthermore, the visual checking followed by disengagement and agitated non-verbal behaviours shown by Jessie are reminiscent of the babies of depressed mothers (Tronick & Weinberg, 1997).

Jessie’s awareness of self was implicit in that her limited use of speech made it difficult for the interaction partner to understand her and any references to self that she might have made. However, her desire to continue communicating during both ‘Still face’ and non- ‘Still Face’ periods and her behaviour during the ‘Still Face’ periods suggested her awareness of herself and of the interaction partner as separate entities.

6.4.1. The relevance of this study to the ‘Collaborative Personhood Model’

Overall these findings support the use of the ‘Still Face’ to highlight both the urge to communicate and the violation of social expectations in human beings. In this case of severe dementia it is clear that the urge to communicate is retained. Whilst speech becomes less efficient as a communication tool, a wide repertoire of verbal and nonverbal behaviours remain that can keep people involved in the social world. In this study, Jessie retained many communication behaviours such as turn-taking, eye contact and conversation-maintenance activities such as nodding. Jessie also spontaneously imitated the investigator’s speech and this functioned as a way for her to maintain a hold on the interaction. In other words, if she lost the thread of the conversation contents, she was able to keep the interaction going by repeating the last word that the investigator said.

The investigator also used verbal imitation to keep the interaction going. In addition, the investigator's verbal imitation may serve to validate the content of Jessie's speech. As such, the communication and personhood is collaborative between the interaction partners. As is typical in severe dementia, Jessie's speech is hard to understand and follow and this often leads to people being excluded from conversations. By contrast, imitation sends the message that the interaction partner understands and a connection has been made. Such 'mirroring' and reflecting back are well-recognised techniques for conveying empathy and maintaining a positive communication environment (Phillipot, Feldman & Coats, 1998). In one instance in the present study Jessie looked at the investigator hands after the investigator had just mirrored Jessie's hand movements then looked at the investigator and smiled. This suggests that reciprocal verbal and non-verbal imitation allows the dyad to experience a collaborative interaction and both are empowered by it.

These findings support the importance of imitation as an intrinsically human activity. It is inevitably shared and provides the basis for both early and future social behaviour. This case study of severe dementia provides further evidence of the universal social function of imitation throughout the lifespan. In contrast to both newborns and children with autistic spectrum disorder, people with severe dementia have had a lifetime's experience of participating in the social world. As such these findings expand the role of imitation to one of maintaining a hold on the social world as well as the previously reported function of providing a way in (Caldwell, 1998; Nadel, 2000). Imitation in this case provides a platform from which both the advantaged and disadvantaged communicators can start in developing collaborative communication and personhood.

6.5. Part Two – The Communication Environment

Having established that Jessie retains an urge to communicate, a repertoire of communication behaviour and an awareness of self and other, this follow-up investigation explores how the environment supports her continued participation in the social world.

6.5.1. Method

Jessie is very mobile and spends much of the day walking around the nursing home. The nursing home has 58 residents and all but one have dementia. The staffing ratio is approximately 1:5 and there is an Activities Coordinator who organises light activities in the home on a daily basis. More structured activities such as baking are organised approximately 3 times a week. Outings are organised every few months but Jessie does not usually participate in these. She has not left the nursing home in the last eight months.

Although Jessie talks a great deal, her speech is extremely difficult to understand. This was reflected in the opinions of staff members who, when asked to comment on Jessie's communicative abilities, tended to focus more on her limitations. Indeed, the majority of the staff members did not believe that Jessie would be able to sit down and participate in an interaction at all.

6.5.1.2. Observation

Jessie was observed over a five-day period to explore her typical opportunities for social interaction in her everyday life. Five recordings were made at different time points over the five days as deemed convenient to the manager and staff of the care home. At these times Jessie's behaviour was recorded as she engaged in her daily

routine. The recordings were organised to continue for 10 minutes each. However, recording ceased if Jessie was removed from the environment for the purposes of receiving personal care, e.g. help to go to the toilet. The shortest recording was 6 minutes long and in order to make them equal in length, the other 4 sessions were also cut to 6 minutes.

The recordings were examined for Jessie's then social context, i.e. what she was doing at the time and her apparent emotional state. Jessie's bids to initiate conversation with other people were then examined and tallied as were responses to her bids by others and bids to initiate conversation with her by others.

6.6. Results

In three of the sessions Jessie was constantly walking up and down the corridor of the nursing home, in the fourth she was at breakfast and in the fifth having her hair washed by care staff. Jessie's communicative bids towards other residents and staff, of those individuals towards her and the context within which these exchanges took place in the sessions are listed below (Table 6.4).

Table 6.4. Jessie's communicative exchanges and the social context in which they occurred

Day	**Social context**	**Emotional state**	**Initiation by Jessie**	**Responses from others**	**Initiation by others**
1	Walking up and down the corridor	Agitated	3	1	1
2	Walking up and down the corridor	Agitated	2	1	1

3	Having her hair washed	Confused and upset	3	3	3
4	Walking along the corridor then sitting in the lounge	Calm	8	0	2
5	Eating breakfast at the table in the dining room	Initially agitated, becoming calmer after eating	6	1	0
Total			22	6	7

Over the five sessions Jessie made a total of 22 attempts to interact with other people (Table 6.4). These bids to initiate social interactions with other people occurred regardless of her apparent emotional state. However, only 6 of her bids to engage people in interaction were responded to (Table 6.4). In 5 of these cases, there occurred no more than 2 conversational turns each between Jessie and the other person. In the 'hair washing' context, Jessie took 33 turns, Carer 1 took 25 turns and Carer 2 took 9 turns. However, this context was task-driven and as such was non-representative of Jessie's typical opportunities to interact.

Jessie appeared to spend a large part of her day attempting to communicate with and being ignored by other individuals, be they staff or fellow residents. Similarly, she received only one-third as many interaction invitations from others as she made (Table 6.4). The following examples indicate how Jessie initiated interactions and how others responded to her.

Example 1:

Failure of others to respond – Session 4

Jessie is walking along the corridor and says something when she walks past another resident. The resident does not respond. She walks into the lounge and sits down to the seat closest to the door next to another resident. They exchange but it can't be heard. The other resident is looking at the investigator who is standing in the doorway. She looks at Jessie and says to the investigator "Who's getting there?"

Jessie sits and stares into space. People are talking all around her but not to her. She says "Smart. Very smart." The woman sitting next to her points and says "There's a seat there." Jessie sits up, looks to where she's pointing and says "Yes, they're very good. In between the letee and the… I can't think. I'll get to it though." The other woman says, "There's a seat over there." "Aye" says Jessie. "They're flaxom when you come in." The other woman looks away and Jessie continues to speak. "Mine's is just in the middle." (Pause) "Very good!" "Oh, yeah." Jessie is staring again. "They've got more, they've got more work done in the last ten minutes." Another lady walking into the room talks to someone on the way past. Jessie thinks she is talking to her and replies (unclear). The same woman is walking back across the room to leave. As she walks past Jessie, Jessie says "That's great. Great! That's marvellous! Is there more than one? Oh, that'd be great! Lovely! Marvellous!" The woman has left the room before Jessie has finished talking. Jessie looks away and stares into the room. "That's great!" Pause, "Makes me any better. It does. Great." She gives a thumbs up and nods her head. (Pause) "Ah-ha! (unclear)".

This passage very clearly indicates Jessie's urge to communicate. However, the fact that her speech is confused makes it difficult for others to respond to her communicative bids. As such, she is frequently ignored by other people.

Example 2:

Task-based communication – Session 3

Carer 1: "Right. Put your head over. Put your head over. Just to get your hair washed."

Jessie: "No, I never put it in there. I didn't like it in there. No, I didn't."

C1 "Come on. Put your head over."

J: "Well wait a minute though and get the thing. "

C1: "That's it."

J: "Don't envy anybody!"

C1: "Put you in a wee bitty. Gonna put your head over?"

J: "Yes."

C1: "That's it. Put your head over. Get your hair done." (Carer pushes Jessie's head over the sink)

J: "Dinnae put your. Dinnae put that other ane in because."

C1: "Put your head over. (To investigator) I'll just let her wander."

J: "I'm sorry about that."

The above example indicates that the nurses had a job to do, i.e. wash Jessie's hair, and that they were focused on that. However, what is also clear is that Jessie did not want to engage in the task although she previously agreed when asked if she wanted her hair washed. In this type of situation it is easy to see how the caregiver might become frustrated with Jessie as she appears to be saying one thing but meaning another. This is very likely to be the result of Jessie's misunderstanding of the situation. For example, she may have understood the question "Do you want your

hair done?" but misunderstood the caregiver's action of pushing her head over the sink.

Example 3

Interaction with investigator

The following example occurred just after a session had been recorded and illuminates Jessie's typical opportunities for interaction and her response to the investigator. In this session Jessie constantly walked up and down the corridor and attempted to open the fire exit doors at both ends. Jessie also talked throughout this period and one particular theme/issue prevailed in her speech. The pitch and volume of Jessie's voice increased and she appeared to become increasingly disturbed as she repeated the same theme. The following passage describes Jessie's behaviour and vocalisations during this period:

Jessie examined a nearby trolley and said, "I don't know where I am. I'll better go this way". She talked to herself constantly, was breathing heavily and was clearly agitated. She walked to the end of the corridor and tried the door. Walking away from the door she said, "Had to take the numbers out. Had to take them out because I had to take three out. I had to give them something to eat. I couldn't take everything from you. I couldn't take all the sugar. I just couldn't do it". She examined the trolley then tried the door again. She said, "I couldn't take the sugar from them – I couldn't possibly". She then said "Thank you very much" as she passed the investigator then returned to the issue that was troubling her in saying, "I couldn't take them all". She tried to open the door again and a nearby nurse shouted her name in an attempt to make her stop. No-one else attempted to communicate with Jessie at this point.

Jessie then walked into the sitting room and sat down. The investigator waited for a few seconds then sat down beside her. The following passage contains strategies of the interaction and how it might be interpreted.

Jessie entered the residents' lounge and began interacting with the investigator and continued to speak about the issue that she was talking about in the corridor. Jessie sat down and said, "Look at that, eh? Yellow!" She was examining her hand and was showing it to the investigator as she moved towards her. "I couldn't take them both. I couldn't take both. I couldn't take both. She continued to examine her hand and counted whilst looking at it. 1, 2, 3, 4, 5, 6, 7, 8, 10, blah, blah, blah." Her voice became louder and more high-pitched as she counted further. As the investigator sat down beside her Jessie's body position immediately relaxed so that she was leaning against the back of the chair. She then made eye contact and said, "I couldn't take both from you darling."

Investigator: *"No, I wouldn't, I wouldn't give you that. That's OK."*

Jessie: "I know you; you would have taken them all."

I: *"Uh-huh."*

J: "Yeah, I know."

I: *"Mhhm. Are you alright?"*

J: "Well, I'm not too bad now."

I: "That's good. That's good."

Phase 2

Jessie told the story behind her distress and her agitation began to reduce.

Jessie: "I couldn't have taken the whole lot."

Investigator: *"No, well no. Nobody would expect you to do that."*

J: "…and he couldn't do it himself."

I: *"Mhhm."*

J: "So I just left the one. A great big one right enough…I couldn't take them all."

I: *"Well, that's OK though isn't it?"*

J: "Yeah."

I: *"That's not a problem. Eh?"*

J: "I thought to myself, well I can't leave them all."

I: *"Mhhm."*

J: "And, I can't leave them all because the both of them is too much for two."

I: *"Mhhm."*

J: "So I'll take, I'll take both of them…and I thought oh they can't, can't do it."

I: *"Mhhm."*

Jessie: "I couldn't do it"

I: *"Mhhm."*

J: "I couldn't have taken two."

I: *"No."*

Phase 3

Jessie continued to tell the story and the issue that was troubling her appeared to resolve.

Jessie: "So he took two and I took a wee one as well."

Investigator: *"Just a wee one."*

J: "Two small ones."

I: *"Mhhm. That's fine though."*

J: "And I gave them two…that'll be one left."

I: *"And that's fair enough and someone else can have that one."*

J: "And that's good of you. He couldn't do it either."

I: *"No. It's too much, eh?"*

J: "Mhhm." (Jessie nods)…"So he's alright…and so was I…he got the same…he was chuffed with himself."

I: *"That's good. So, he's leaving one for somebody else?" (Jessie nods).*

J: "So we're both three and three and three and…three each."

I: *"You're equal."*

J: "So he's alright."

I: *"Mhhm. That's good. That's good."*

J: "So he's reading two and I'm reading two…and he's very happy about it."

I: *"That's good. And are you happy about it?"*

J: "Yes."

I: *"That's good."*

Jessie may have been thinking about an upsetting incident/time in her life. She felt she was unable to do what was expected of her, i.e. "I couldn't take them all". She was becoming increasingly upset as a result of thinking about it. She was, however, willing to discuss the issue with someone but no-one was available to talk

to her at that point. When someone did respond, in this instance the investigator, Jessie was able to 'talk-through' the issue and after a few minutes her agitation decreased. The process of working through her anxiety is noticeable in the words she uses. For example, she went from using phrases like "I couldn't take them all" to "So, he's quite happy" and "So, we've got both each". From this we can infer that Jessie was telling a story of how she managed to resolve a situation with another person that occurred at some earlier time in her life.

6.7. Discussion and Relevance of This Study to the 'Collaborative Personhood Model'.

The aim of this follow-up study was to explore how the environment supports Jessie's continued participation in the social world. Example 1 provided an illustration of the failure of those around her to respond to her communicative bids. Jessie made attempts to engage others during this session but she was largely ignored by other residents and members of staff. Example 2 highlighted the difficulties that can arise in task-based activities with people with severe dementia. Jessie was clearly unsure of the situation and was unhappy with carers' attempts to wash her hair. It is easy to see how mutual misunderstandings and frustrations can occur in such a task-driven situation with a person with severe dementia. However, carers are often untrained in dementia-specific care and residential homes are typically understaffed, thereby preventing optimal treatment of the person with dementia. Example 3 showed how via collaborative communication with a supportive interaction partner, Jessie was able to improve her emotional state and conceivably resolve an internal issue that she was unable to verbalise. Although her speech was difficult to comprehend it was possible to decipher some words and themes in her discourse. Reflecting these back

to Jessie both validated her emotional state and provided her with the means to fully express it.

The following study looks at the facilitation of communication and self expression in a person at a very severe stage of dementia who has no retained speech.

CHAPTER SEVEN

STUDY 4 - INTENSIVE INTERACTION IN VERY SEVERE DEMENTIA: A CASE STUDY

7.1. Introduction

By the time dementia reaches the later stages, people with a diagnosis may appear to be completely unreachable, which results in those who care for them no longer attempting to engage them in interactions (Kitwood, 1997). The communication problems experienced by people with very severe dementia clearly have a huge impact both on them and on those who care for them. For families, communication difficulties put a major strain on maintaining relationships with the person with dementia. Care staff however, face the challenge of establishing relationships with people whose communication skills are already severely compromised when they first meet. As such, communication and social interactions are extremely difficult and may cease altogether except in pursuance of basic activities of daily living (Bowie & Mountain, 1993). This situation is clearly unsatisfying for both people with dementia and those who care for them.

Improving interpersonal communication in this situation could improve the job satisfaction of care staff and the quality of life of people with dementia (Woods, 1999). The challenge is how to facilitate communication when people with dementia have little or no speech and may only make sounds or repeat isolated words or movements. It is argued, however, that even at this severe stage people retain many identifiable communication skills (Orange & Purves, 1996) and demonstrate a continued urge to communicate and interact with others (Ellis & Astell, 2004). These retained behaviours could form the basis of an intervention designed specifically for

individuals with very severe dementia that has the potential to enhance their lives and the lives of those who care for them.

Such benefits and positive effects on communication are clearly very desirable for people with very severe dementia, who are frequently excluded from the social world. Intensive Interaction (II) is an approach to interacting with people with severe communication problems that was developed in the 1980's for people with profound learning disabilities. The focus of II is on regular non-verbal and subvocal exchanges with little or no involvement of speech between two people, one of who experiences difficulty communicating with others. The quality of the interaction is all-important in II, and there is no emphasis on task performance or achieving specific outcomes (Nind, 1999). The key to II is that the behaviour of the nonverbal participant is viewed as intentionally communicative. This links to Newson's (1978) 'as-if' theory on the communication between parents and infants (section 1.2).

7.1.1. Intensive Interaction in Autistic Spectrum Disorder

The basic principles of Intensive Interaction reflect the essential communicative processes that occur early in life between caregivers and infants (Nind, 1999). Although the structure and the linguistic contents of these early exchanges are non-verbal, few people would argue that they are without meaning or emotion (Papousek, 1995; cited in Duffy, 1999). Furthermore, Nind (1999) asserted that this similarity in approaches does not mean that people with learning disabilities or, by extension, other severe communication impairments, should be regarded or treated as if they were infants.

II commences with the professional or caregiver becoming familiar with the person they want to communicate with and the types of interactions that this person

might engage in. This initial 'connection' is then developed into a set of spontaneous interactive 'games' that are based on the behaviour of the person with communication impairment. For example, a sound or action they make, such as banging on the table, might be reflected back by their partner, either directly or with some variation in the rhythm. The professional or caregiver responds contingently to her partner's behaviours to continuously expand the interactions between them and support their partner to take a more active role in communication.

As II has developed over the years, different aspects of the basic approach have been emphasised. Hewett (1996) and Nind (1999), for example, both consider the focus of II to be on teaching the pre-speech fundamentals of communication. These fundamentals include turn-taking, shared attention, and eye gaze, which are developed together by the two communication partners (Nind, 1999). In this approach the professional or caregiver is termed the 'teacher' and the communication-impaired partner the 'learner'. The teacher constantly modifies her own interpersonal behaviours such as body language, eye gaze, vocalisations and facial expressions in order to make them as engaging and as meaningful as possible to their communication-impaired partner. It is important for the teacher to be attentive to their partner's behaviour, to create pauses in the interaction and to be open to joining in with rhythms and sounds their partner may make. This may include imitation of certain strategies of the communication-impaired partner's behaviour and vocalisations.

In Caldwell's (2005; Caldwell & Horwood, 2007) version of II imitation is the starting point of capturing the communication partner's attention and of entering into their world (Caldwell, 2008). Caldwell's' approach to II emphasizes exploring the sensory experience of people with profound communication difficulties and

attempting to ‘learn their language’ (Caldwell & Horwood, 2007). One key outcome of this approach is providing a way for people typically regarded as outside the social world to express themselves (ibid). This is commonly seen in shifts from solitary self-stimulatory behaviour, such as biting or head banging to engagement in shared activity (Caldwell & Horwood, 2007). By responding in ways that are familiar to the person with severe communication difficulties, i.e. initially imitating and then developing them into a shared ‘language’, it is possible to build and sustain close relationships without speech (Caldwell, 2005).

Studies using II typically employ video-recording to measure developments in communicative responses (e.g. Kellett, 2000; 2003; Nind, 1996). For example, Nind (1996) examined engaged social interaction, smiling, eye contact and looking at the communication partner’s face. The efficacy of II in increasing the occurrence of such social behaviours in people with severe learning disabilities has been demonstrated in numerous studies (e.g**.** Watson & Fisher, 1997; Stothard, 1998; Samuel & Maggs, 1998). Additionally, several government bodies have noted other benefits of II, including improved quality of life (QCA, 2001a; 2001b; Ofsted, 1997; 2000).

As aforementioned (section 3.5.) some individuals at very severe stages of dementia exhibit persistent bodily movements (Kitwood, 1997) which are thought to be–stimulatory in nature and occur in response to the failure of the environment to provide the person with dementia with occupation and a feeling of security (Perrin, 2001). In the absence of speech, these self-stimulatory behaviours may potentially be used as a basis of communication between people with severe dementia and their caregivers. As such, II then appears to have great potential for improving communication between people with very severe dementia and those who care for them. To investigate the usefulness of II for facilitating communication with people

with severe dementia a single case study was conducted which was guided by principles from both of the variants of II discussed above. Caldwell's (2005; 2007) approach to II with its focus on matched responsiveness and nonverbal behaviour was felt to be best suited to exploiting any retained communication behaviours of people with very severe dementia who no longer have speech. However, Hewett and Nind's (1998) work, which focuses on the pre-speech fundamentals of communication, can be seen as providing a framework for identifying retained communication behaviours.

7.1.2 Study aims

In this pilot study the investigator applied the principles of II to communicating with an individual with severe dementia in order to explore her retained communicative repertoire. The outcome of this technique was compared to a Baseline (Standard Interaction) situation within which the investigator asked the participant a range of closed questions in an attempt to recreate a 'typical' interaction. The verbal and non-verbal communicative responses of the participant were coded and analysed between II and Standard Interaction (SI) conditions.

7.2. Method

7.2.1. Participant

Edie is an 81-year old lady who has dementia that has reached a very severe stage and as such was put forward by her daughter as a possible participant in this study. Edie started to lose speech some years ago but coped initially with everyday tasks such as shopping by writing a list and giving it to an assistant. Later on in her illness Edie began to engage in less functional activity, such as going out to look for her daughter at her place of work in the middle of the night. She eventually became

unable to look after herself at home and was admitted to a local care home. Five years on Edie has no speech at all and is unable to walk. She spends most of the day in bed or in front of the television in the residents' lounge. She receives regular visits from her daughter.

7.2.1.1. Ethical approval

Ethical approval for the study was received from the MREC designated to consider research proposals covered by Section 51 (3) (f) of the Adults with Incapacity (Scotland) Act 2000. See Appendix I for approval letter.

7.2.1.2. Ethical Procedure

In accordance with this legislation, consent for Edie to participate was sought from her nearest family member, her daughter. The ethical approval included video-recording the interactions with Edie and her daughter also consented to this. Still images of Edie and the investigator are used throughout this chapter to visually illustrate the nature of the interactions. Edie's daughter gave permission to use these images in this thesis and Edie's identity has been protected throughout by obscuring her eyes.

7.2.2. Procedure

Learning Edie's Language:

<u>Stage 1 – current communication context</u>

The first step in learning Edie's language was to explore her current communication context. This involved spending two days in the care home observing the everyday activities and communication that took place. Additional information on

her communicative abilities was collected from the manager of the care home and some of the staff. This highlighted that the team responsible for providing Edie's care found it difficult to communicate with her and engage her in activities of daily living such as eating, bathing and toileting. Edie's daughter was also interviewed as part of understanding her current communication context. Her daughter identified a number of Edie's own behaviours that she felt had communicative value for Edie, including a high-pitched sound, sucking and chewing her thumb and laughing.

Stage 2 – SI session

The next step in learning Edie's language was to collect Baseline data on Edie's communicative behaviour. For this a 10-minute session was devised where the investigator went into Edie's room to conduct a spoken conversation consisting of the sort of questions typically asked in day-to-day interactions observed in the care home. These included: "Did you enjoy your meal?"'; "Did you have a lie in this morning?" and "Have you seen the weather outside today?" Each of these closed questions was followed by a 20 second pause to give Edie the best possible opportunity to respond in some way, for example by nodding or shaking her head. See Appendix IV for a full list of the questions used.

Stage 3 – II session

Step three of learning Edie's language was to attempt to communicate with her using her own behaviours or language as the basis of the interaction (Caldwell, 2005; 2007). For this the investigator again allowed 10-minutes to go into Edie's room to conduct a session where the investigator attended to and imitated Edie's verbal and non-verbal behaviours. For example, if Edie made a vocalisation, the investigator

may have attempted to imitate it directly or to reproduce the rhythm of it in some way, for example by tapping it out on the side of the bed. As such, the investigator focused on learning Edie's communicative repertoire and reflecting it back to her in a way that was potentially meaningful to her.

7.3. Results

7.3.1. Edie's Language

Based on the evidence gathered from the three stages – 1) observation and interviews; 2) SI; and 3) II; Edie's communication repertoire was found to encompass direction of eye gaze, sounds, movements, facial expressions, and several fundamental strategies of communication. These are summarised in Table 7.1.

Table 7.1. Edie's communication behaviours

Category	**Behaviour**		
Eyes	Gaze on partner/partner's eyes	Gaze elsewhere	Eyes closed
Sounds	High-pitched sound	Laughter	Silence
Movements	Sucking and chewing the side of her thumb	Moving her head closer or further away from partner	Moving her head to touch her partner
Facial expressions	Surprise	Smile	Neutral
Fundamental strategies	Initiation/introduction of behaviour	Reciprocation of partner's behaviour	Turn-taking

The investigator examined the occurrence of these 15 different behaviours across the two one-to-one sessions. The patterns of these behaviours were quite different across the two sessions both in their presence and absence and of the frequency with which they occurred. To illuminate this the two sessions are briefly described below, starting with the investigator. Time checks are included at points where new behaviours occurred or old behaviours ceased in an attempt to clarify the way each session unfolded. In addition, the patterns of occurrence are displayed for each session (see Figures 7.3. and 7.4.). For simplicity, Figures 7.3. and 7.4. are records of whether a behaviour occurred during each minute of the two 10-minute sessions and are neither counts of frequency nor duration.

7.3.2. Session 1 – SI

When the investigator entered her room Edie was lying in her bed, which had padded cot-sides. She was lying on her side on two pillows and her eyes were open. When the investigator asked the first question Edie made a high-pitched sound and fixed her gaze on the investigator. She continued to make the high-pitched sound intermittently whilst looking at the investigator. Edie's behaviour in response to the investigator talking to her, i.e. making a sound and maintaining direct eye contact, suggested that she wanted to interact.

At 37 seconds into the session Edie became silent and at 39 seconds into the interaction, she closed her eyes. These behaviours could be taken to indicate disengagement by Edie. However, after a few more seconds she opened her eyes and with a surprised expression made the high-pitched sound. The investigator continued to ask the prepared questions at 20-second intervals. Edie kept her gaze fixed on the investigator and at 51 seconds, she began chewing her thumb (Figure 7.1). This

activity was one previously identified by Edie's daughter as an indicator of boredom and may have served as a comfort behaviour for Edie (Coia & Jardine, 2008).

Figure 7.1. Edie sucking and chewing her thumb during the SI

At 62 seconds into the ten-minute session Edie closed her eyes and continued to chew her thumb for another 5 seconds. She then removed her thumb from her mouth and her eyes remained closed for the rest of the session (Figure 7.2). The investigator continued to ask the prepared questions allowing time between each for Edie to respond but *she never again opened her eyes, moved or made a sound* during the remainder of the session.

Figure 7.2. Edie with her eyes closed during the SI

The total interaction lasted for barely one minute of a planned ten-minute session. The exchange revealed that although Edie appeared to respond to speech at the outset of the session (Figure 7.3.), the investigator's speech alone failed to maintain her participation. This session confirmed the reports from staff of the difficulties they experienced in communicating with Edie in regard to basic activities of daily living. However, the session also contained a number of behaviours, e.g. high-pitched sound and thumb chewing, that Edie's daughter had suggested have a communicative value. These stood out as exactly the sort of behaviours that are used in II to develop an interaction.

Category	Minute	1	2	3	4	5	6	7	8	9
Eyes	Eye contact with partner									
	Gaze elsewhere									
	Eyes closed									
Sound	High-pitched sound									
	Laughter									
	Silence									
Movements	Chewing thumb									
	Moving closer/away									
	Touching partner									
Facial expressions	Surprise									
	Smile									
	Neutral									
Communication Fundamentals	Initiation									
	Reciprocation									
	Turn-taking									

Figure 7.3. Presence and absence of Edie's communication behaviours during each minute of the SI session.

7.3.3. Session 2 - II

At the start of this session Edie was lying in her bed with the padded cot-sides. She was lying on her side on two pillows dozing. After 16 seconds Edie opened her eyes and looked directly at the investigator and made 'her' sound in a high-pitched tone. The investigator immediately reflected the sound and pitch back to her. Edie then repeated the sound and both partners each took another 2 turns each in this manner. As in the Standard session, Edie's immediate reaction to the investigator speaking was to look at her and make the high-pitched sound. In this session,

however, rather than continuing to speak, the investigator adapted her response to match Edie's, which resulted in a brief initial 'dialogue' of several turns each.

At 23 seconds into the interaction, the dialogue changed when Edie put her thumb in her mouth and started sucking and chewing on it, all the time looking into the investigator's eyes. The investigator responded by sucking and chewing her thumb. Edie then removed her thumb from her mouth and made her high-pitched sound. The investigator responded by taking her thumb from her mouth and repeating the sound made by Edie. Edie then put her thumb back into her mouth, and the investigator followed suit. In these exchanges Edie took the lead by introducing a new behaviour (thumb-chewing), then reverting to the previous behaviour (high-pitched sound) then returning to thumb chewing, all the while looking intently at the investigator. The investigator responded to each of these changes by matching Edie's behaviour.

The investigator then attempted to change the dialogue by removing her thumb from her mouth and making a sound like Edie's high-pitched one. In response Edie then removed her thumb from her mouth and matched the sound and she and the investigator then continued to turn-take making this sound for another 20 seconds. This section of dialogue ended when Edie began sucking her thumb again. In this exchange the investigator reintroduced one of Edie's behaviours (high-pitched sound) and Edie responded by altering her own behaviour to match hers.

At 90 seconds into the 10-minute session, the investigator attempted to change the interaction again by introducing a new element. This was to imitate the rhythm of Edie's thumb chewing through tapping her fingers on the side of the bed. Edie continued to chew her thumb and stared intently at the investigator. After a few seconds, Edie removed her thumb from her mouth and made her high-pitched sound.

The investigator stopped tapping and repeated the vocal sound and turn-taking resumed using Edie's sound until the investigator tapped on the bed again. Edie became silent, put her thumb back in her mouth and watched the investigator's fingers tapping on the bed. She then removed her thumb from her mouth and resumed her high-pitched sound. At 108 seconds, Edie put her thumb in her mouth and immediately removed it when she saw the investigator do the same. Edie and the investigator then resumed turn taking with her sound.

In this phase, when the investigator introduced the new element (rhythmic tapping) there was no discernable change in Edie's behaviour. She continued to chew her thumb while looking intently at the investigator. However, as the investigator continued to tap, Edie then stopped chewing and made her high-pitched sound. She did not put her thumb in her mouth again during this session. The turns in this exchange suggest that the introduction of a variation of one her behaviours (thumb-chewing) had less impact for Edie than the matched behaviour. However, she appeared to retain her interest in the interaction as she continued to look at the investigator and finally reintroduced a previous behaviour (high-pitched sound).

Edie and the investigator continued the dialogue making the high-pitched sound until 150 seconds into the session, at which point Edie introduced another new behaviour. She lifted her head up from the pillows and moved towards the investigator's hand, which was resting on the cot-side. Edie rubbed her forehead on the investigator's hand and the investigator responded by stroking Edie's hair. The investigator then attempted to reintroduce one of Edie's previous behaviours, i.e. her thumb-sucking and the rhythm of it. Again, Edie raised her head, rubbed her forehead against the investigator's hand and then closed her eyes. The investigator then made Edie's sound towards her to which she reciprocated followed by a number of turns

each. Edie continued to keep her eyes closed for 43 seconds during this part of the interaction.

This phase of the session was notable for Edie introducing touch into the interaction. The dialogue had been proceeding through sound and vision (eye contact) when Edie opened up a third channel of communication, i.e. touch. However, although the investigator responded by touching Edie's head, the investigator did not match her behaviour, as she had done with Edie's sound.

Category	**Minute**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
Eyes	Eye contact with partner									
	Gaze elsewhere									
	Eyes closed									
Sound	High-pitched sound									
	Laughter									
	Silence									
Movement	Chewing thumb									
	Moving closer/away									
	Touching partner									
Facial expressions	Surprise									
	Smile									
	Neutral									
Communication fundamentals	Initiation									
	Reciprocation									
	Turn-taking									

Figure 7.4. Presence and absence of Edie's communication behaviours during each minute of the II session.

After the sound turn-taking, Edie then rubbed her head against the investigator's hand for a third time and the investigator moved forward and rubbed her head against

Edie's. At this point, Edie opened her eyes and gave a look of surprise followed by the high-pitched sound. The dialogue then took on the form of a spontaneous game of mutual head touching and vocalisation. During this phase Edie laughed at several points after she and the investigator touched heads (Figure 7.5).

Figure 7.5. Edie and the investigator touching heads during the II Sessions.

This is perhaps the most exciting part of the interaction as this is when Edie exerted the most control over the situation and was the most animated. Edie was clearly attempting to get closer to and to touch the investigator. However, initially the investigator failed to detect this and was focused on maintaining previous strategies of the interaction. Once the investigator recognised Edie's new direction, the interaction took on a new dynamic. From the moment the investigator touched heads with Edie, their communication became much more playful. They took turns with sounds and touching and both laughed at several points throughout (Figure 7.6.).

Figure 7.6. Edie and the investigator laughing during the II Session.

At 7 minutes and 4 seconds into the interaction, Edie fell silent and closed her eyes. She remained like this until the investigator touched her head 46 seconds later, at which point she made her sound and then opened her eyes when the investigator reciprocated with the sound. Edie and the investigator began turn-taking again using Edie's sound and both laughed several times. At 9 minutes and 1 second, Edie fell silent and then closed her eyes 5 seconds later. She remained like this for the rest of the session. This section suggests that perhaps Edie was ready to end the interaction at a point before the investigator realised. The investigator attempted to keep the interaction going and Edie reciprocated with enthusiasm for a while but closed her eyes again very soon after. Edie closing her eyes effectively ended the interaction and can be seen as another element of her communication repertoire.

At the start of both sessions Edie made eye contact with the investigator and a high-pitched sound. In the SI Session, however, Edie quickly stopped making any

sound or eye contact and at 67 seconds into the 10 minutes, effectively disengaged from the interaction. By contrast in the II Session, the investigator's reciprocation of Edie's initial communication bids, led to turn-taking and a rather more intimate interaction.

7.4. Discussion

The occurrence of eye contact and the high-pitched sound at the start of both sessions suggests that in both instances Edie wished to communicate with the investigator. This confirms earlier findings that the urge to communicate is retained even in the severe stages of dementia (Astell & Ellis, 2006). In addition, when Edie's daughter viewed the videos she reported that this was also how her mother behaved when she visited.

As well as using sound and eye contact to establish communication, Edie effectively used several different channels of communication during the two interactions with the investigator. In the Standard session she closed her eyes and became silent – i.e. she ceased making her two "I want to interact" behaviours – very quickly and withdrew from the interaction. By contrast, in the II session, Edie's high-pitched sound formed the initial exchange with the investigator, effectively enabling them to say 'hello'.

Throughout the rest of the II Session, Edie used her eyes and her sound to communicate. The investigator also used the high-pitched sound both in turn-taking initiated by Edie and to restore their exchange at several points, e.g. when rhythmic tapping did not elicit a response from Edie. In addition to her eyes and sound, Edie introduced movement and touch, which served to change and intensify the

interaction. Once the investigator reciprocated Edie's touch, the exchange became playful and elicited expression of positive emotion, i.e. laughing.

In addition to new behaviours appearing as the II exchange progressed, it was notable that Edie discontinued chewing her thumb, a behaviour that appeared early in both sessions. Thumb-chewing could serve a number of different functions for Edie. Her daughter, for instance, suggested that it is an indicator of boredom. This fits with the notion that such behaviour is a way that people "talk to themselves" which enables them to return to their 'comfort zones' (Coia & Jardine, 2008). It is possible, that Edie ceased chewing her thumb during the II session because she no longer needed to 'talk to herself'. However, in the Standard session Edie closed her eyes and became silent when she stopped chewing her thumb. Together these behaviours signaled disengagement and served to terminate her involvement in the interaction. The idea that Edie's behaviour has multiple meanings and that behaviour combining occurs suggests that she retains at least some of the basic components of communication and interaction with another person.

Other fundamental aspects of communication behaviour such as initiation, turn-taking, using emotional facial expressions (e.g. surprise) and expressing emotion (e.g. laughter) can be seen in Edie's communication repertoire. This supports previous findings that even in the severe stages of dementia, people retain the pre-speech fundamentals of communication (Ellis & Astell, 2004; Orange & Purves, 1996). In addition, Edie is able to lead the interaction in several different ways. One was by initiating new behaviours, e.g. thumb-sucking, moving towards partner. She is also able to reintroduce old behaviours (thumb-sucking, high-pitched noise) at various points in the interaction. Finally, she is able to end the interaction by closing her eyes and falling silent.

7.4.1. The relevance of this study to the 'Collaborative Personhood Model'

These findings suggest that Edie not only has a retained communication repertoire but also can engage in social interaction and express herself. This was supported by the reaction of Edie's daughter on viewing the video recordings of the two sessions. She confirmed that Edie is very responsive to her when she visits and that her interactions with her mother contain similar strategies such as moving her face very close to Edie's. She also reported that holding Edie's hand, cuddling her and talking to her all resulted in what she interpreted to be a happy and animated response. On watching the video recordings, Edie's daughter realised that she copied some of her mother's communicative behaviours when they were interacting without knowing that she was doing it.

Edie's daughter consented to the care home manager viewing the video recordings. The manager's reaction was primarily one of surprise and extreme emotion. She commented that she had never seen Edie communicate so readily and with such obvious engagement. These reactions from Edie's daughter and the care home manager, suggest that using the principles of II to facilitate communication between people with very severe dementia such as Edie and those who care for them would indeed be beneficial. In particular, II has the potential for training and supporting care staff, who may find it very difficult to know how to respond to people such as Edie who make sounds and repetitive behaviours. It could hopefully give them the confidence to interact with these people who they currently avoid or ignore due to their own discomfort (Kitwood, 1990).

In order to respond to the communication needs of people with very severe dementia some modification of II is required. Specifically, due to the severe memory problems experienced by people with dementia, II with this population must remain

‘in the moment’ with no need for any parts of previous interactions to be remembered. Therefore, the communication partner must remain ‘adaptive’ to the changes in communication by the person with dementia and be willing to start afresh each time. As such, this approach will hereafter be referred to as Adaptive Interaction (AI).

AI based on Caldwell’s behavioural-matching version of II, appears to have potential as a tool for promoting and supporting communication between people with very severe dementia and those who care for them. This case study uncovered a retained communication repertoire including sounds, movement and eye gaze as well as other basics of communication such as turn taking and facial expressions (Hewett, 1996; Nind, 1996). The following study explores the further application of AI in a small group of people with very severe dementia.

CHAPTER EIGHT

STUDY 5 - ADAPTIVE INTERACTION IN VERY SEVERE DEMENTIA

8.1. Study Aims

Study 5 was designed as a follow-up and expansion to the case study in Chapter 7. In this study AI is used in an attempt to learn the communicative repertoires of five people with very severe dementia, including Edie, who have very little or no retained speech. Secondly, Adaptive Interaction is also used to explore the potential for engaging the participants in meaningful, shared activity. Third, Adaptive Interaction is used to allow people with very severe dementia to express their sense of self. The following research questions were posed:

Are there differences in the

1. *types* and

2. *amount* of communicative behaviours between Standard and Adaptive Interaction sessions for people with very severe dementia?

3. Are there any similarities in behaviours between participants with very severe dementia?

4. How do people with very severe dementia indicate a retained sense of self?

As the role of the interaction partner is crucial to the success of Adaptive Interaction, the investigator's own communicative behaviours were also examined. As such, the following questions were asked regarding the investigator's behaviour:

Are there differences in the

5. *types* and

6. *amount* of communicative behaviours between Standard and Adaptive Interaction sessions for the interaction partner?

7. How can the interaction partner facilitate communication and the maintenance of self in people with very severe dementia?

8.2. Method

8.2.1. Participants

All potential and eventual participants are resident in 2 long-term care facilities and have been living in this environment for a number of years. The managers of both care facilities were asked to identify those residents who were at a severe stage of dementia and who had very little or no retained speech. Two people with severe dementia were observed in the training phase and were found to have retained a significant level of functional speech. These individuals were therefore deemed to have moderately severe dementia and were excluded from the study itself. Six participants (2 men) with severe dementia were originally scheduled to take part in the study. Only one of these individuals was independently mobile, 4 were largely confined to bed for most of the day and one participant spent most of the day in the sitting room confined to her wheelchair. One of the potential participants continually fell asleep during attempts to engage him in both Standard and Adaptive Interaction sessions. Subsequently, data collection was ceased with this participant leaving 5 people (1 man) with severe dementia taking part in the study. The mean age of the participants was 82.6 years and all met the NINCDS-ADRDA criteria for probable AD (McKhann et al, 1984).

8.2.1.1. Ethical approval

Ethical approval for the study was received from the MREC designated to consider research proposals covered by Section 51 (3) (f) of the Adults with Incapacity (Scotland) Act 2000. See Appendix I for approval letter.

8.2.1.2. Ethical procedure

The same ethical procedure was completed for this study as in Chapter 7. In accordance with the Adults with Incapacity (Scotland) Act, 2001, consent for people with severe AD to participate was sought from the nearest family member. The ethical approval from the MREC included video-recording the interactions.

8.2.2. Procedure

Participants were observed by the investigator and one other trained observer using the 'Direct Observation of Behaviour' observation instrument devised by Bowie & Mountain (1993) (Table 8.1).

Table 8.1. The 'Direct Observation of Behaviour' instrument (Bowie & Mountain, 1993).

Category	Description of behaviours
A Self-care	Independent participation in activities of daily living – this includes eating, drinking, dressing, washing and purposeful movement
B Social engagement	Any activity where the patient is appropriately and actively engaged with the environment – this includes participating in

	social activities, making conversation, reading and watching television.
C Reception of care	Activities where patient is being treated/cared for by staff and is not displaying independence
D Motor activity	Unnecessary, often excessive, movement and activity – this includes aimless wandering, restlessness, rocking, fidgeting and repetitive movements
E Antisocial	Behaviours which violate, or cause distress to, others – this includes physical and verbal aggression, screaming or shouting and stealing
F Inappropriate	Behaviours which would normally be seen as unacceptable, but do not violate others – this includes sucking fingers, urinating inappropriately, spitting or throwing food an the floor and talking to oneself
G Neutral	Patient is detached from the environment – this includes sitting or standing and doing nothing and sleeping

This observation phase allowed data to be collected that reflected the daily activity and interaction patterns of the participants, thereby providing a picture of their daily routines. Table 8.1 shows the behavioural categories and descriptions of those behaviours operationalised by Bowie & Mountain (1993). The description of behaviours in the first 3 categories (i.e. 'self care', 'social engagement' and 'reception of care') use adjectives that suggest positive behaviours (i.e. 'independent', 'purposeful', 'appropriately', 'actively', 'cared for') behaviours that might normally be regarded as 'acceptable' or 'typical' of people with dementia in a residential home.

Conversely, the remaining 4 categories (i.e. 'motor activity', 'antisocial', 'inappropriate', 'neutral') use more negative descriptors (i.e. 'unnecessary', 'excessive', 'aimless', 'violate', 'cause distress', 'aggression', 'unacceptable', 'inappropriately', 'detached'), suggesting behaviours that may appear to be meaningless and/or problematic to caregivers.

The observers spent two days in a local care home observing two people with moderately severe dementia. Each participant was observed every 20 minutes throughout the course of a typical 9am-4pm day. Subsequently, the observers noted down the behaviour of one participant every 10 minutes (see above for observation sheet). Agreement between the observers was 100%.

A small-n design was employed in this study and data was analysed using a randomisation test as described by Todman & Dugard (2001). The IV in the study was the interaction type and the DV was the change in social behaviours. The two conditions in this study were the same as stages 2 and 3 that were employed in study 5.

The running order of the sessions was randomised according to the guidelines for small n studies as stated by Todman & Dugard (2001). A timetable of sessions was planned with the manager of the care facility which would cause minimal interruption to the participants' daily routines. As such, sessions were organised to take place between 10 am and 12.30 pm (between breakfast and lunchtime) and 1.30 pm and 4 pm (between lunch and dinnertime). The family caregivers of people with severe dementia were contacted via 2 local care facilities for older people. Caregivers were provided with all information on the study and were asked to give consent for the investigator to approach their loved-one. Owing to the level of cognitive impairment experienced by people with severe dementia, family caregivers were

asked to give proxy consent to take part and were invited to be present when the study took place. In cases where this was unfeasible, professional caregivers of the people with dementia were invited to observe the sessions. It was estimated that family and professional caregivers were best placed to recognise any signs of distress in each individual participant. All sessions were video recorded and participants were filmed interacting with the investigator in baseline Standard Interaction (SA) conditions where the investigator attempted to engage the person with dementia in conversation and in treatment Adaptive Interaction (AI) conditions when the principles of II were employed. Professional and family caregivers were invited to give their opinion on the effectiveness of the treatment approaches and to comment on any changes they might observe in the communicative behaviour of the person with dementia. However, this part of the procedure was conducted on an ad hoc basis and was largely determined by the immediate availability of professional and family caregivers. Each session was organised to run for 10 minutes or for as long as the person with dementia continued to interact. Sessions were interrupted for the following reasons: participant fell asleep during session (n=5); participant unwell (n=1); participant stops interacting (n=1). Table 8.2 shows the running order and duration of sessions for all participants.

Table 8.2. The running order and duration of sessions for all participants.

Participant	**Session number**	**Session type**	**Duration**
1	1	S	10 minutes
	2	S	10 minutes
	3	A	10 minutes

	4	A	10 minutes
	5	A	Asleep at 4min 05 secs
	6	A	Not conducted due to ill health of person with dementia
2	1	S	10 minutes
	2	S	10 minutes
	3	S	10 minutes
	4	A	10 minutes
	5	A	10 minutes
	6	A	10 minutes
3	1	S	10 minutes
	2	S	10 minutes
	3	S	Asleep at 1 min 05 secs
	4	A	10 minutes
	5	A	10 minutes
	6	A	10 minutes
4	1	S	10 minutes
	2	S	Asleep at 5 min 20 secs
	3	S	10 minutes
	4	S	Asleep at 3 min 38 secs
	5	A	10 minutes
	6	A	10 minutes
5	1	S	10 minutes
	2	S	10 minutes

	3	S	Disengaged at 9 minutes 13 secs
	4	A	10 minutes
	5	A	Asleep at 4 min 41 secs
	6	A	10 minutes

8.2.3. Behavioural coding

Three minutes from the beginning of each clip was selected for coding so as to eliminate loss of data from sessions that were cut short. In other words, 3 minutes was the shortest session. Microanalytic coding categories were developed from a combination of those identified in the case study and those employed in previous studies on II (see Watson & Fisher, 1997; Stothard, 1998; Samuel & Maggs, 1998). Thus the clips were coded for eye gaze, facial expression, vocalisations, physical contact, gestures and imitation in both interaction partners (Table 8.3).

Table 8.3. The main behavioural coding categories and corresponding subvariables used in the main study.

Communicative behaviour	**Sub variable**
1. Eye gaze	Eyes closed
	Elsewhere
	Looking at partner's body/face
	Eyes
	Can't tell
2. Facial expressions	Neutral
	Smiling
	Frowning
	Surprise
	Other

3. Vocalisations	Silence
	Vocalisation
	Laughter
	Other (i.e. coughing)
4. Physical contact	Contact occurs (decided by the instigator of contact)
	No contact (decided by the person who ceases contact)
	Unknown
5. Gestures	Pointing
	Nodding
	Shaking head
	Other
6. Imitation	Investigator imitates person with dementia
	Person with dementia imitates investigator

Evaluation of the AI communication technique (Treatment condition) in comparison to the SI (Baseline condition) was conducted using The Observer (version no. 5) behavioural video coding equipment that allowed detailed analysis of the participants' reactions. For example, behaviours such as eye gaze, vocalisations and bodily movements were compared across the Baseline and Treatment conditions.

8.2.4. Interrater reliability

The practicalities of the coding categories and their operational definitions were discussed at length by two independent raters prior to the coding of the videotapes. A practice session that was not included in the final data set was also used by the raters to examine the efficacy of the categories.

One independent rater coded 100% of the videotapes for verbal and non-verbal communicative behaviours. Four sessions were selected at random and were coded by a second rater thus allowing kappa values to be calculated for 4 sessions coded by both raters. The Cohen's kappa values were calculated as follows: session 1(Participant 4/Standard): 0.91; session 2 (Participant 1/Adaptive): 0.58; session 3 (Participant 5/Adaptive): 0.80; session 4: (Participant 3/Standard): 0.59. Landis and Koch (1977) suggested that a kappa value of equal to or less than 0.20 indicates slight agreement; 0.21-0.40, fair agreement; 0.41-0.60, moderate agreement; 0.61-0.80, substantial agreement; and 0.81-1.00, almost perfect agreement. In adherence with this, the interrater reliability for this study can be assumed to range from moderate to almost perfect agreement.

8.3. Results

Observational Data

The use of the 'Direct Observation of Behaviour' observation instrument (Bowie & Mountain, 1993) produced a picture of the daily routines of the participants. Figure 8.1 shows the activity patterns for all 5 participants.

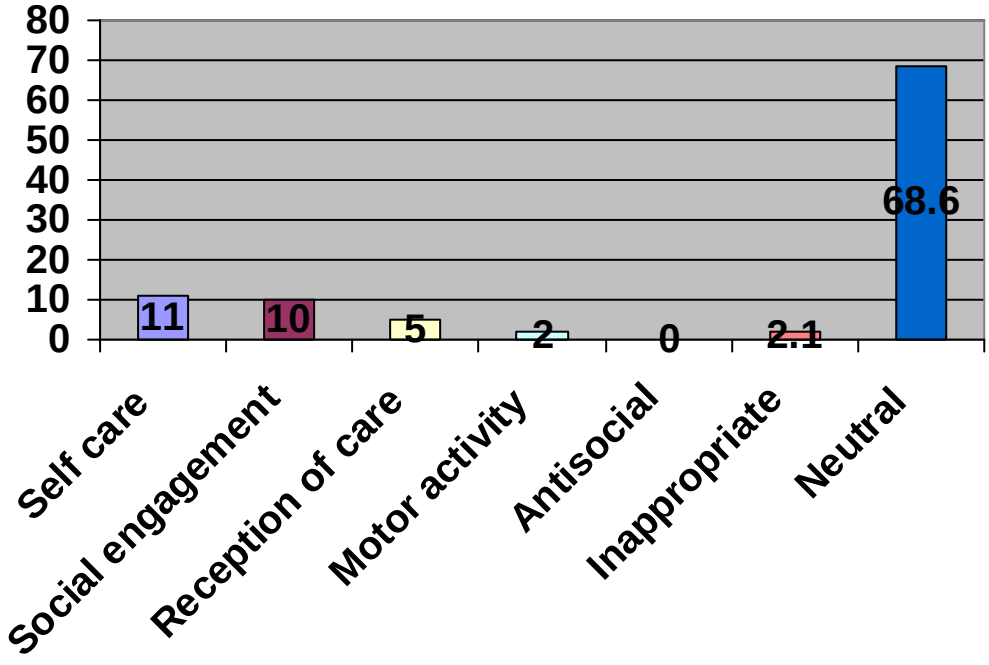


Figure 8.1. The percentage of each activity category for all 5 participants using the 'Direct Observation of Behaviour' observation instrument (Bowie & Mountain, 1993).

Use of the 'Direct Observation of Behaviour' observation instrument (Bowie & Mountain, 1993) indicated that the participants spent the biggest part of the day in a 'neutral' state. In other words, for 68.6% of day, the participants were 'detached from the environment' and were most often sleeping or doing nothing. This finding stood out as all other activity categories composed only 11% (i.e. 'self care') or less of the day. 'Social engagement' came just below 'self care' at 10% indicating that participants spent only one tenth of the waking day in non-functional interaction with others. The next highest percentage was 'reception of care' at 5%. This finding largely reflected the level of assistance that the participants required to eat and drink at meal times. 'Motor activity' (2%) and 'inappropriate' behaviour (2.1%) comprised very little of the day and 'antisocial' behaviour did not appear at all. These findings

illustrate that very little of the participants' time was spent engaged in behaviours that might be deemed 'out of place'.

8.3.1. Communicative behaviours

Direction of eye gaze

The mean duration (seconds) and standard deviation (SD) of each session person with dementia and investigator spent with their 'eyes closed', looking 'elsewhere', at the 'partner's body or face', at the partner's 'eyes' or when the coder was unable to tell the direction of gaze in both SI and AI is shown in Table 8.4.

Table 8.4. The mean duration and SD of direction of 'eye gaze' between SI and AI conditions.

	Closed		**Elsewhere**		**Body/face**		**Eyes**		**Can't tell**	
People with dementia	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Standard	10.9	19.8	58.1	32	10.9	19.8	58.1	32	1.9	7.6
Adaptive	4.7	6	55.5	37.8	4.7	6	55.5	37.8	6.3	15.5
Investigator										
Standard	0	0	**20.9	7.3	0	0	**20.9	7.3	0.39	0.82
Adaptive	0.4	1.2	**16	26.4	0.4	1.2	**16	26.4	1.2	4.64

*Means significantly different at: *p<.05; **p<.01*

As seen in Table 8.4., the randomisation test indicated non-significant differences in direction of gaze duration for '*eyes closed*' in both people with dementia (p>.05) and the investigator (p>.05). This finding was replicated for looking '*elsewhere*' in people with dementia (p>.05), however findings highlighted a significantly higher duration of the investigator looking '*elsewhere*' in SI sessions (p<.001). The randomisation test also revealed a significantly higher duration of people with dementia looking at '*partner's body/face*' in the SI condition (p<.001) but no significant difference for the same gaze category was found for the investigator (p>.05). Although the analysis for looking at the '*eyes*' indicated no significant difference between conditions for people with dementia (p>.05), findings revealed that the investigator looked significantly more at her partner's '*eyes*' in the AI condition (p<.05).

Facial expressions

The mean duration (seconds) and SD of each session people with dementia and investigator maintained facial expressions of 'neutral', 'smiling', 'surprise' and 'other' is shown in Table 8.5.

Table 8.5. The mean duration and SD 'facial expression' between Standard and Adaptive conditions.

	Neutral		**Smiling**		**Surprise**		**Other**	
People with dementia	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Standard	*88.8	25.1	***2.8	5	0.3	1	7.5	25.6
Adaptive	*69.6	33.6	***33.2	38.8	0.2	0.8	5.8	19.3

Investigator	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Standard	60.9	39.5	33.2	38.8	0	0	5.8	19.3
Adaptive	41.7	39.4	38	34.4	0.9	2	13	28.6

*Means significantly different at: *p<.05; ***p<.001*

As seen in Table 8.5., the randomisation test showed a significantly higher duration of a 'neutral' facial expression for people with dementia in Standard than in Adaptive sessions (p<.05) and a significant increase in 'smiling' for people with dementia in Adaptive sessions (p=<.001). However, the randomisation test indicated non-significant differences (p-values >.05) in duration of all 4 categories of facial expression for the investigator. For the people with dementia, the results also showed non-significant differences between conditions for 'surprise' and 'other'.

Vocalisations

The mean duration (seconds) and SD of each session people with dementia and the investigator spent in 'silence', 'vocalising', 'laughing' and engaged in an 'other' type of vocalisation is shown in Table 8.6.

Table 8.6. The mean duration and SD of 'vocalisations' between SI and AI conditions.

	Silence		**Vocalising**		**Laughing**		**Other**	
People with dementia	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Standard	78	25	***18.8	23.9	0.9	2	2.3	4.9
Adaptive	78	15	***18.9	14.9	2.5	4.2	0.5	1
Investigator	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Standard	***92.4	3.1	***6.9	2.7	*0.6	1	0	0
Adaptive	***80.9	8.9	***15.6	8.1	*2.9	3.8	0.5	1.3

*Means significantly different at: *p<.05; **p<.01; ***p<.001*

With regards to 'vocalisations', the randomisation test showed significant increases in 'vocalising' in AI sessions for both people with dementia (p<.001) and the investigator (p<.001). For the investigator there was significantly more 'silence' in SI sessions (p<.001), and significantly more 'laughter' (p<.05) in the AI. The randomisation test indicated non-significant differences (p-values >.05) for 'silence', 'laughing' and 'other' in people with dementia and also for 'other' in the investigator between SI and AI sessions.

Bodily contact

The mean duration (seconds) and SD of each session people with dementia and the investigator spent in 'bodily contact' is shown in Table 8.7.

Table 8.7. The mean duration and SD of 'bodily contact' between SI and AI conditions.

	Bodily contact	
People with dementia	Mean	SD
Standard	0	0
Adaptive	8.6	18.8
Investigator		
Standard	3.5	11.3
Adaptive	15.5	25.8

As seen in Table 8.7., the randomisation test indicated non-significant differences (p-values >.05) in duration of 'bodily contact' between SI and AI Interaction sessions for both people with dementia and the investigator.

Gestures

The number of occurrences and SD's in each session that the people with dementia and investigator spent 'pointing', 'nodding', 'shaking head' and displaying an 'other' gesture is shown in Table 8.8.

Table 8.8. The number of occurrences and SD's of direction of 'gestures' between Standard and Adaptive conditions.

	Pointing		**Nodding**		**Shaking head**		**Other**	
People with dementia	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Standard	0.6	1.6	1.9	2.9	1.7	3.7	4.7	4.3
Adaptive	0.7	1.6	0.9	1.4	0.5	0.7	11.8	10.2
Investigator								
Standard	0	0	1.6	2	0	0	4.2	5.9
Adaptive	0.6	1.3	1.4	1.8	0	0.2	14	9.1

The randomisation test indicated non-significant differences (p-values >.05) in amount or type of 'gestures' between SI and AI sessions for both people with dementia and the investigator

Imitation

The amount of times and SD in each session that the people with dementia and the investigator spent 'imitating' the other is shown in Table 8.9.

Table 8.9. The mean and SD of instances of ‘imitation’ between SI and AI conditions.

	Imitation	
People with dementia	Mean	SD
Standard	*0.1	0.3
Adaptive	*1.7	2.3
Investigator		
Standard	***1.9	3.1
Adaptive	***24	8.9

*Means significantly different at: *p<.05; ***p<.001*

As seen in Table 8.9., the randomisation test showed significant increases in the amount of imitation in both people with dementia ($p<.05$) and the investigator ($p<0.001$) in AI.

8.4. Discussion

The primary purpose of study 5 was to examine the possibility of facilitating the communicative potential between people with severe dementia and their caregivers. In so doing the investigator used ‘Adaptive Interaction’ (AI), a technique developed in the previous case study. The research questions asked if there were any differences in the types and/or the amount of communicative behaviours between SI and AI sessions and were there any similarities in communicative behaviours within a group of people with severe dementia and their interaction partner? Although the simple answer to these questions is affirmative, the individual findings are complex and for the sake of clarity will be discussed with regard to the categories within which they were analysed.

8.4.1. Communicative behaviours

Eye gaze

There were no significant results with regards to 'eyes closed' in either people with dementia or investigator; looking 'elsewhere' in people with dementia; looking at 'partner's body/face' in investigator; or for 'eyes' and 'can't tell' in people with dementia between session types. However, the results indicated a significantly greater amount of people with dementia looking at 'partner's body/face' in SI sessions; for investigator looking 'elsewhere' indicating a significantly greater amount in SI sessions; at her partner's 'eyes' and when her gaze was occluded ('can't tell') which both showed a significant increase in AI sessions.

The finding that people with dementia looked more at 'partner's body/face' in SI sessions seems to be somewhat anomalous. One might have expected that people with dementia looking at the 'partner's body/face' would have occurred more often in the AI sessions as the interaction partner should have been more engaging to them. However, if this finding is examined alongside that which shows the interaction partner looking 'elsewhere' more often in the SI sessions it could suggest that the people with dementia were looking more intently at the interaction partner in an attempt to find out what she was looking at or doing. This looking 'elsewhere' finding for the interaction partner was likely to have occurred as a result of her glancing at the stopwatch in order to keep the timing constant between the questions in the SI session. It could be argued therefore that the people with dementia were curious as to the function of the direction of the interaction partner's gaze. In other words, the people with dementia may have been asking themselves, "What is she looking at?" This finding reflects those of Nadel et al (2000) in that the participants in

her study also displayed curious behaviour and at times followed her gaze. Following on from this, the finding that the interaction partner looked more often at the people with dementia's eyes in AI than SI sessions makes sense as the interaction partner was focused on the people with dementia's communicative behaviours and attempting to engage them with those. This finding indicates the investigator's adherence to Nind's (1999) and Hewett's (1996) guidelines for using the principles of II.

With regards to facial expression, there were no significant differences in any of the four categories of facial expression for the investigator or for 'surprise' or 'other' in people with dementia. However, the results indicated a significantly higher duration of the 'neutral' facial expression for people with dementia in SI than in AI sessions and a significant increase in 'smiling' for people with dementia in AI sessions. These two findings are extremely encouraging as they suggest a distinct lack of expressions in SI sessions whilst marking the appearance of a positive example in AI sessions. Also of interest here is that the interaction partner did not smile more often in AI than SI sessions. This finding suggests that people with dementia were not imitating this expression; rather they were more likely to have been independently expressing their own enjoyment of the interaction.

The results for vocalisations indicated no significant differences in 'silence', 'laughing' or 'other' in people with dementia and for 'other' in the interaction partner between SI and AI sessions. However, the results revealed a significant increase in 'vocalising' for both people with dementia and the interaction partner in AI sessions. This finding suggests increased engagement and social behaviour for both communication partners in AI sessions. These findings are supported by the interaction partner displaying more 'silence' in SI sessions and more 'laughter' in the AI sessions.

The differences in duration of 'bodily contact' between SI and AI sessions for both people with dementia and the interaction partner were non-significant. This finding suggests that perhaps touch is not a method of communication that is easily accessible to people with dementia or to me perhaps owing to the constraints of the bodily positions of both partners.

With reference to gestures, the differences in the amount or type were non-significant between SI and AI sessions for both people with dementia and the interaction partner. Although the people with dementia and the interaction partner did indeed display the use of gestures, the result itself may have been confounded by the types of gestures that were selected for coding.

The results showed significant increases in the amount of imitation in AI sessions in both people with dementia and the interaction partner. These findings are perhaps the most interesting of all. One would indeed have expected the interaction partner to use imitation more often in AI sessions as it is one of the main tenets of the approach. However, it is much more meaningful to find this result in people with dementia. This finding suggests that imitation is a feasible way for people with very severe dementia to communicate with others.

Adaptive Interaction based on Caldwell's (1998) behavioural-matching version of II, appears to have potential as a tool for promoting and supporting communication between people with severe dementia and those who care for them. This research uncovered a retained communication repertoire including sounds, movement and eye gaze as well as other basics of communication such as turn taking and facial expressions (Hewett, 1996; Nind, 1996).

8.4.2. The relevance of this study to the 'Collaborative Personhood Model'

This study provides further evidence for the collaborative nature of personhood and the importance of social interaction, even in the most severe stages of dementia. In the absence of speech, people with very severe dementia were able to engage in dyadic exchanges with a communication partner based on nonverbal communication. These confirmed their continued personhood and suggested also continued awareness of self and other.

The findings also support the proposal that speech is not a necessary requirement for the existence and experience of self-awareness. In the absence of speech, Adaptive Interaction provided a mechanism for people with very severe dementia and no functional speech to demonstrate self-awareness and continued personhood.

Finally, this study highlights the necessity for interaction partners to be responsive and adaptive to the needs of nonverbal people with dementia. Providing a supportive and facilitating communication environment can enable people, even in the very severe stages of dementia, to demonstrate their continued personhood in social interactions with another human being.

CHAPTER NINE

GENERAL DISCUSSION

9.1. Conclusion

The aim of this thesis was to explore the maintenance of personhood and self-image in dementia by way of collaborative communication between people with dementia and their caregivers/interaction partners. As such, the roles of the person with dementia (as the disadvantaged communicator) and the interaction partner (as the advantaged communicator) were examined in each study. Three main strands of the communication process between people with dementia and their caregivers were examined in this thesis. Firstly, the communication changes that occur as the illness progresses and those skills are maintained were identified. Secondly, the relationship between retained communication skills and the self were examined and finally, the crucial role of the advantaged interaction partner in facilitating and maintaining communication and self with people with dementia was investigated. As such, this thesis explored a range of collaborative methods designed to facilitate selfhood and communication and between people with a diagnosis and their caregivers/interaction partners at different points in the illness. The view of communication as a socially collaborative process that occurs between communication partners tied the thesis together.

As dementia progresses, people experience many communication difficulties however a range of communication functions are also retained throughout the illness. The identification and development of these remaining skills increased the probability of mutually rewarding interactions occurring between people with AD and their

interaction partners. By utilising these retained skills via collaborative communication, the interaction partner facilitated the expression and maintenance of self-image in people with dementia. Therefore, interventions that aim to promote communication in people with AD must maximise these intact functions (Azuma & Bayles, 1997). As such, for people with mild to moderate dementia, communication may be focused on activities that are speech-based. However, for people with severe dementia who have little or no retained speech, non-verbal strategies have been shown to be more appropriate in achieving mutually meaningful interactions.

Previously discussed models of communication and personhood (sections 1.2 -1.6) have taken into account the collaborative nature of communication and personhood. However, intersubjectivity is achieved in these models via verbal communication. However, in the absence of language, this must be achieved by non-verbal methods. As such, the advantaged communication partner must remain open to the communicative behaviours of disadvantaged communicator. The advantaged communication partner must then attempt to learn and use the language of the disadvantaged communicator. As such, the advantaged communicator uses his "creativity to establish a new channel of communication" (Kitwood, 1997, p.3.) and as such strives to achieve the 'least collaborative effort' (Clark & Wilkes-Gibb, 1986).

The 'Collaborative Personhood Model' of communication and personhood combines vital elements of previously discussed work by Rommetveit (1974), Vygotsky (1978), Trevarthen (2001), Buber (1967) and Clark & Brennan (1991). However, this model differs from previous ones in that 'the between', 'intersubjectivity' and 'personhood' can also be achieved via non-verbal communication. Non-verbally, 'the between' is more likely to involve the shared

expression of emotions in the moment. Nevertheless, for the ultimate aim of personhood to be achieved either verbally or non-verbally the communication between interaction partners must be collaborative in nature.

9.2. Limitations and critique

Perhaps the main criticism that may be levelled at this thesis is the appropriateness of having a single investigator (with the exception of study 2) acting as the sole interaction partner to all participants. As such, one might question the potential generalisation of the results in situations where other communication partners are involved. A single investigator was used across the studies as for three main reasons. First of all, the investigator has a wealth of experience in working and communicating with people with dementia. More specifically, she has worked for Alzheimer Scotland in both paid and voluntary roles in the past and has worked with people with dementia as a researcher for over eight years. As such the investigator is well versed in facilitative strategies and is aware of and sensitive to the communicative needs of people with dementia. Therefore, she was in a position to exercise and explore the concept of 'collaborative communication' whilst remaining sensitive to the communicative bids of participants. Secondly, a single investigator was used in this thesis as a means of exerting a modest amount of control over the studies as a whole. In short all participants engaged with one individual, thereby ruling out the impact of differing knowledge bases and approaches that may have been used by other interaction partners. Thirdly, training other interaction partners to engage with people with dementia using 'collaborative communication' was out with the scope of this thesis. However, this is something that will be explored by the investigator in her future research. In keeping with this line of reasoning is the fact

that the investigator conducted the majority of the data analysis and interpretation of findings. One might argue that positive bias might come into play in such circumstances. However, lengthy coding discussions between the investigator and the independent raters and interrater reliability procedures minimised any bias that might have impacted upon the findings. The wide range of methodologies used in studies 1-5 may also be called into question by the reader. However, each study was designed with specific questions in mind. For example, study 2 used a non-experimental design within which cause and effect were not addressed. This methodology enabled the investigator to look at individual differences in e.g. repeated themes, and provided a more natural setting for participants than an experimental situation. Study 2 employed a within design where participants served as their own controls. This methodology allowed a comparison between situations where family members communicated with each other and those where the main interaction partner was the investigator. Owing to the mainly non-significant results in studies 1 and 2, the use of statistical analytic methods in these cases may be regarded as a limitation. Analysing at a group rather than an individual level in study 1 was conducted in order to uncover differences in dependent variables between stages of dementia. However, small numbers in two of the levels addressed and variation in data meant that parametric tests had to be employed. As such, the fine detail of the data may have been better explored via individual cases.

Studies 3 and 4 employed a case study approach as this served as the first attempt at using II with people with dementia. As such, the case study was used to suggest avenues for further investigation. Single case design can be considered to be unethical as the results may not be generalisable to other individuals. However, to conduct a large group study which does not take individual differences may be

regarded to be inappropriate as it may miss out on potential benefits to individuals. In keeping with this train of thought, study 5 used a small n within participants experimental design where people served as their own controls. This approach enabled the investigator to demonstrate that the results of study 4 can apply to other individuals. However, one might also argue that analysing the data at a group level may have lost out on some of the fine detail that may have been more apparent at the individual case study level. As such, an analysis of the dependency between sequential data points and between interaction partners in this study would have provided a deeper level of understanding of the interactions.

9.3. Future Directions

What was clear from the studies in this thesis is that as dementia becomes more severe, the more creative the advantaged interaction partner must be. As aforementioned, the more advanced the individual's dementia is, the more difficult it is to communicate with her and therefore facilitate her personhood. As such, my future research in this area will focus on individuals with very severe dementia and the co-creation of personhood via the 'Collaborative Personhood Model' to make this possible.

References

Aalten, P., van Valen, E., Clare, L., Kenny, G. & Verhey, F. (2005). A review of clinical correlates. *Aging and Mental Health*, 9 (5), 414-422.

Abad, V. (2002). Reaching the Socially Isolated Person with Alzheimer's Disease Through Group Music Therapy - A Case Report. *Voices: A World Forum for Music Therapy*. Retrieved July 20, 2007, from http://www.voices.no/mainissues/Voices2 (3) Abad.html

Alberoni, M. A., Baddeley, A., Della Salla, S., Logie, R., & Spinnler, H. (1992). Keeping track of a conversation: impairments in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 7, 639-646.

Allender, J., & Kazniak, A. W. (1989). Processing of emotional cues in patients with dementia of the Alzheimer type. *International Journal of Neuroscience*, 46(3-4), 147-155.

Almberg, B., Grafstrom, M. & Winblad, B. (1997). Major strain and coping strategies as reported by family members who care for aged demented relatives. *Journal of Advanced Nursing*, 26, 683-691.

Alpert, M., Rosen, A., Welkowitz, J. & Lieberman, A. (1990). Interpersonal communication in the context of dementia. *Journal of Communication Disorders*, 23, 337-346.

American Psychiatric Association. (1987). Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, revised. Washington, D.C.: American Psychiatric Association, 1987.

Astell, A. J., & Ellis, M. P. (2006). The social function of imitation in severe dementia. *Infant and Child Development*, 15, 311-319.

Astell, A. J., Alm, N., Gowans, G., Ellis, M., Dye, R., & Vaughan, P. (2008, online). Involving older people with dementia and their carers in designing computer-based support systems: Some methodological considerations. *Universal Access in the Information Society*.

Astell, A. J., Ellis, M. P. & Hockey, H. J. (2004). Social cognition in dementia. *Journal of Cognitive Neuroscience*, supplement, 126.

Astell, A. J., Ellis, M. P., Bernardi, L., Bowes, M., Tunnard, C., & Webb, H. (2005). A review of the needs of people with dementia and their caregivers. Dementia Research Group, School of Psychology, University of St. Andrews.

Astrom, S., Nilsson, M., Norberg, A., Sandman, P-O., & Winblad, B. (1991). Staff burnout in dementia care – relations to empathy and attitude. *International Journal of Nursing Studies*, 28 (1), 65-75.

Azuma, T., & Bayles, J. A. (1997). Memory impairments underlying language difficulties in pAD. *Topics in Language Disorders*, 18, 58-71.

Baddeley, A.D., & Hitch, G. (1974). *Working memory*. In G.H. Bower (Ed.), *The psychology of learning and motivation: Advances in research and theory*, 8, 47-89. New York: Academic Press.

Baines, S., Saxby, P., & Ehlert, K. (1987). Reality orientation and reminiscence therapy: a controlled cross over study of elderly confused people. *British Journal of Psychiatry*, 151, 222-231.

Batty, M., & Taylor, M. J. (2003). Early processing of the six basic facial emotional expressions. *Cognitive Brain Research*, 17(3), 613-620.

Bayles, K. A. & Tomoeda, C. K. (1991). Caregiver report of prevalence and appearance order of linguistic symptoms in Alzheimer's patients. *The Gerontologist*, 31(2), 210-216.

Bayles, K. A., & Tomoeda, C. K. (1994). *The functional linguistic communication inventory*. Tucson, AZ: Canyonlands Publishing.

Bayles, K.A. (2003). Effects of working memory deficits on the communicative functioning of Alzheimer's dementia patients. *Journal of Communication Disorders,* 36, 209-219.

Bell, J. & McGregor, I. (1995). A challenge to stage theories of dementia. In T. Kitwood & S. Benson (eds) *The New Culture of Dementia Care.* London: hawker.

Berg, A., Hansson, U, W. & Hallberg, I. R. (1994) Nurses' creativity, tedium and burnout during 1 year of clinical supervision and implementation of individually planned nursing care: comparisons between a ward for severely demented patients and a similar control ward. *Journal of Advanced Nursing,* 20, 742-749.

Bird, M. (2002). Challenging behaviour in dementia: A critical role for psychology. *Australian Psychologist,* 34 (2), 144-148.

Bohling, H.R. (1991). Communication with Alzheimer's patients: an analysis of caregiver listening patterns. *International Journal of Aging & Human Development,* 33(4), 249-67.

Bourgeois, M .S. & Mason, L .A. (1996). Memory wallet intervention in an adult day-care setting. *Behavioural Interventions,* 11, 3-18.

Bourgeois, M. S. (1990). Enhancing conversation skills in patients with Alzheimer's disease using a prosthetic memory aid. *Journal of Applied Behaviour Analysis*, 23, 29-42.

Bourgeois, M. S. (1992). Evaluating memory wallets in conversations with persons with pAD. *Journal of Speech and Hearing Research,* 35, 1344 -1357.

Bourgeois, M. S. (1993). Effects of memory aids on the dyadic conversations of individuals with pAD. *Journal of Applied Behaviour Analysis.* 26, 77-87.

Bourgeois, M. S. (1994). Teaching caregivers to use memory aids with patients with dementia. *Seminars in Speech and Language.* 15 (4), 291-305.

Bourgeois, M. S., Dijkstra, K., Burgio, L. & Allen-Burge, R. (2001) Memory aids as an augmentative and alternative communication strategy for nursing home residents with pAD. *Augmentative and Alternative Communication,* 17, 196-210.

Bowie, P., & Mountain, G. (1993). Using direct observation to record the behaviour of long stay patients with dementia. *International Journal of Geriatric Psychiatry*, 8, 857-864.

Brooker, D., (2004). What is person-centred care for people with dementia? *Reviews in Clinical Gerontology, 13,* 215-222.

Brown, B. R. (1970). Face-saving following experimentally induced embarrassment. *Journal of Experimental Social Psychology,* 6, 255-271.

Buber, M. (1937). *I and Thou*, translated by Ronald Gregor Smith. New York: Scribners, 1958, 1984.

Bucks, R. S.; Singh, S.; Cuerden, J. M. & Wilcock, G. K. (2000). Analysis of spontaneous, conversational speech in pAD of Alzheimer type: Evaluation of an objective technique for analysing lexical performance. *Aphasiology,* 14, 71-91.

Burgio, L. D., Engel, B. T., Hawkins, A., McCormick, K. & Scheve, A. (1990). A descriptive analysis of nursing staff behaviours in a teaching nursing home: Differences among NA's, LPN's, and RN's. *The Gerontologist*, 30, 107-112.

Caldwell, P. (1998) *Person to Person: Contact and Communication with People with Profound Disabilities.* Pavilion Publishing, Brighton.

Caldwell, P. (2005). *Finding You Finding Me: Using Intensive Interaction to get in touch with people whose severe learning disabilities are combined with autistic spectrum disorder*. Jessica Kingsley Publisher.

Caldwell, P. (2008). Intensive Interaction; Getting in Touch with a Child with Severe Autism. S. Zeedyk (Ed). *Techniques for promoting social engagement in individuals with communicative impairments.* Jessica Kingsley Publishers.

Caldwell, P., & Horwood, J. (2007). *From Isolation to Intimacy: Making Friends without Words.* Jessica Kingsley Publisher.

Carstensen, L. L., Fisher, J. E. & Malloy, P. M. (1995). Cognitive and affective characteristics of socially withdrawn nursing home residents. *Journal of Clinical Gerontology*, 1, (3), 207-218.

Chappell, N. L. & Novak, M. (1992). The role of support in alleviating stress among nursing assistants. *The Gerontologist*, 32 (3): 351-359.

Chatterjee, A., Strauss, M. & Smyth, K.A et al. (1992) Personality changes in Alzheimer's disease. *Archives of Neurology*, 49, 486-491.

Clark, H. H., & Brennan, S. E. (1991). Grounding in communication. In L. B. Resnick, J. M. Levine & S. D. Teasley (Eds.), *Perspectives on socially shared cognition.* Washington, DC:APA.

Clark, H. H., & Wilkes-Gibbs, D. (1986). Referring as collaborative process. *Cognition,* 22, 1-39.

Cohen, G.D. (2000). Two intergenerational interventions for Alzheimer's disease patients and families. *American Journal of Alzheimer's Disease,* 15, 137-142.

Coia, P. & Jardine, A. (2008). Developing Relationships with People with Profound Learning Disabilities Through Intensive Interactions. S. Zeedyk (Ed). *Techniques for promoting social engagement in individuals with communicative impairments.* Jessica Kingsley Publishers.

Constable, J. F. & Russell, D. W. (1986). The effect of social support and the work environment upon burnout among nurses. *Journal of Human Stress,* Spring.

Davidson, F. G. (1995). *Alzheimer's: A practical guide for carers to help you through the day.* London: Judy Piatkus.

Day, C.R. (1997) Validation Therapy: A Review of the Literature. *Journal of Gerontological Nursing*, 23(4): 29-34.

de Vries, B., Blando, J. A., & Walker, L. J. (1995). An exploratory analysis of the content and structure of the life review. In B. K. Haight & J. D. Webster (Eds.), *The art and science of reminiscing: Theory, research, methods, and applications* (pp. 123-137). Washington, DC: Taylor and Francis.

Dijkstra, K., Bourgeois, M.S., Allen, R.S. & Burgio, L.D. (2004). Conversational coherence: discourse analysis of older adults with and without dementia. *Journal of Neurolinguistics*, 17, 263-283.

Downs, M. (2005). Awareness in dementia: In the eye of the beholder. *Aging & Mental Health*, 9 (5): 381-383.

Duffy, M. (1999). Reaching the Person behind the Dementia: Treating comorbid affective disorders through subvocal and nonverbal strategies. Hand book of Counselling and Psychotherapy with Older Adults, Duffy, M., John Wiley & sons, NY.

Ellis, M. P. & Astell, A. J. & (2008). Promoting communication with people with severe dementia. S. Zeedyk (Ed). *Techniques for promoting social engagement in individuals with communicative impairments.* Jessica Kingsley Publishers.

Ellis, M. P. & Astell, A. J. (2004). The urge to communicate in severe dementia. *Brain and Language,* 91 (1), 52-52.

Feil, N. (1993). *The Validation Breakthrough*. Baltimore, MD: Health Professions Press.

Finnema, E., Dröes, R-M, Ribbe, M., & Van Tilburg, W. (1999). The effects of emotion-oriented approaches in the care for persons suffering from pAD: a review of the literature. *International Journal of Geriatric Psychiatry*, 15, 141-161.

Folstein, M. F., Folstein, S. E. & McHugh, P. R. (1975). Mini-mental state - a practical method for grading the cognitive state of patients for the clinician. *Journal of psychiatry*, 12, 189-198.

Garcia, L. J. & Orange, J. B. (1996) The analysis of conversational skills of older adults: current research and clinical approaches. *Journal of Speech-Language Pathology and Audiology*, 20 (2).

Garcia, LJ, & Joanette, Y. (1997). Analysis of conversational topic shifts: A multiple case study. *Brain and Language*, 58, 92–114.

Goffman, E. (1955). On face-work: an analysis of ritual elements in social interaction. *Psychiatry*, 18, 213-31.

Goffman, E. (1959). *The Presentation of Self in Everyday Life*. Doubleday: Garden City, New York.

Gold, D.P., Andres, D. & Arbuckle, T.Y. (1994). Verbosity in older adults. In M.L. Hummert, J.M. Wiemann & J.F. Nussbaum (Eds.) *Interpersonal communication in older adulthood: Interdisciplinary theory and research (pp. 107-129).* Thousand Oaks, CA: Sage.

Goldwasser, A. N. & Auerbach, S. M. (1996). Audience-based reminiscence therapy intervention: effects on the morale and attitudes of nursing home residents and staff. *Journal of Mental Health and Aging*, 2, 101-113.

Guendouzi, J.A. & Muller, N. (2001). Intelligibility and rehearsed sequences in conversations with a DAT patient. *Clinical Linguistics and Phonetics*, 15, (1 & 2) 91-95.

Haden, C.A. (1998). Reminiscence with different children: Relating maternal stylistic consistency and sibling similarity in talk about the past. *Developmental Psychology*, 34, 99-114.

Head, D. M., Portnoy, S. & Woods, R, T. (1990). The Impact of reminiscence in two different settings. *International Journal of Geriatric Psychiatry*, 5, 295-302.

Hepburn, K. W., Tornatore, J., Center, B. & Ostwald, S. W. (2001) Dementia family caregiver training: affecting beliefs about caregiving and caregiver outcomes. *Journal of the American Geriatrics Society*, 49: 450-457.

Hern, B.G. & Weis, D.M. (1991). A group counseling experience with the very old. *The Journal for Specialists in Group Work,* 16(3), 143-151.

Hewett, D. (1996) 'How to do Intensive Interaction', In Collis, M. & Lacey, P. 1996 (Eds.) *Interactive Approaches to Teaching: A Framework for INSET*, London: David

Hobson, P (1993). *Autism and the development of mind.* Hillsdale, NJ: Lawrence Erlbaum Assoc.

Intensive Interaction website. Retrieved June 16, 2004, from http://www.intensiveinteraction.co.uk/page.php?p=4

Kellett, M. (2000). Sam's story: evaluating Intensive Interaction in terms of effect on the social and communicative ability of a young child with advanced learning difficulties. *Support for Learning*, 15 (4), 165-171.

Kellett, M. (2003). Jacob's journey: Developing sociability and communication in a young boy with severe and complex learning difficulties using the intensive interaction teaching approach*. Journal of Research in Special Educational Needs*, 3(1), 116-121.

Kiernat, J. (1979). The use of life review activity with confused nursing home residents. *The American Journal of Occupational Therapy* 33, 306-310.

Kitwood, T. (1990). The dialectics of dementia: with particular reference to Alzheimer's disease. Ageing and Society, 10, 177-196.

Kitwood, T. (1993). Person and process in dementia. *International Journal of Geriatric Psychiatry*. 9, 541-5

Kitwood, T. (1993). Discover the person, not the disease. *Journal of Dementia Care,* 1 (1), 16-17.

Kitwood, T. (1997). Dementia reconsidered: The person comes first. Buckinghamshire.

Kitwood, T., & Bredin, K. (1992). Towards a Theory of Dementia Care: Personhood and Well-being. *Ageing and Society*, 12, 269-287.

Koretsky, P. (2001). Using photographs in a therapeutic setting with seniors. *Afterimage,* 29 (3), 8.

Krauss, R.M. (2005). The psychology of verbal communication. In, N. Smelser & P. Baltes (eds.), *International Encyclopedia of the Social and Behavioral Sciences.* London: Elsevier.

Landis JR, Koch GG. (1977) The measurement of observer agreement for categorical data. *Biometrics*, 33,159 -174.

Lesser, R. and L. Milroy (1993). "Linguistics and Aphasia", Longman, London

Lubinski, R. (1999). Learned helplessness: Application to communication of the elderly. R. Lubinski, *Dementia and Communication.* Singular: New York.

Lubinski, R. (Ed.) (1995). *Dementia and Communication*. San Diego: Singular Publishing Group, Inc.

Lubinski, R. B. (1979). Why so little interest in whether or not old people talk: a review of recent research on verbal communication among the elderly. *International Journal of Aging and Human Development,* 9 (3), 237-245.

MacDonald, G. & Leary, M. R. (2005). Why does social exclusion hurt? The relationship between social and physical pain. *Psychological Bulletin,* 131 (2), 202-223.

March, E. G., Pattison, P. & Wales, R. (2009). The role of cognition in context-dependent language use: Evidence from Alzheimer's disease. *Journal of Neurolinguistics,* 22, 18-36.

Mayhew, P.A., Acton, G.J., Yauk, S. & Hopkins, B.A. (2001). Communication from individuals with Advanced DAT: Can it Provide Clues to Their Sense of Self-Awareness and Well-Being? *Geriatric Nursing,* 22 *(2),* 106-110.

McDaniel, K.D., Edland, S.D. & Heyman, A. (1995). Relationship between level of insight and severity of dementia in Alzheimer disease. CERAD Clinical Investigators. Consortium to Establish a Registry for Alzheimer's Disease. *Alzhiemer's Disease and Associated Disorders,* 9 (2), 101-104.

McGlynn, S.M., & Kaszniak, A.W. (1991). When metacognition fails: Impaired awareness of deficit in Alzheimer's disease. *Journal of Cognitive Neuroscience,* 3, 184-189.

McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., & Stadlan, E. M. (1984). Clinical diagnosis of the NINCDS-ADRDA work group under the auspices of department of Health and Human Services task force in Alzheimer's Disease. *Neurology, 34,* 939-947.

Meltzoff, A. N. & Moore K. M. (1983). Newborn infants imitate facial gestures. *Child Development,* 54, (3), 702-709.

Mentis, M; Briggs-Whittaker, J; Gramigna, GD. (1995). Discourse topic management in senile dementia of the Alzheimer's type. *Journal of Speech and Hearing Research.* 38, 1054–1066.

Merriam SB, Cross L., (1982). Adulthood and reminiscence: A descriptive study. *Educational Gerontology* 8, 275-290.

Moniz-Cook, E., Jarvis, K., Lawley, D., Pratt, R., Woodhouse, J., Luter, C., Richards, K. & Duggan, P. (2001). Interventions in challenging behaviour in dementia in residential homes: the role of therapeutic collage. Great Britain: Health Action Zone, 2001.

Moniz-Cook, E. (2002). Supporting staff caregivers in residential and nursing homes. *Signpost*, 7, (2) 19–21.

Nadel, J. Croue, S., Mattlinger, M-J., Canet,P., Lecuyer, C. & Martini. (2000). Do children with autism have expectancies about the social behaviour of unfamiliar people? A pilot study using the ''still face'' paradigm. *Autism*, 4(2), 133-146.

Neal, M. & Briggs, M. (2004). Validation therapy for dementia (Cochrane Review). In: *The Cochrane Library*, Issue 2. Chichester, UK: John Wiley & Sons, Ltd.

Newson, J. (1978). Dialogue and development. In A. Lock (Ed.) *Action, gesture and symbol: The emergence of language.* New York: Academic Press.

Nind, M. (1996). 'Efficacy of Intensive Interaction: Developing sociability and communication in people with severe and complex learning difficulties using an approach based on caregiver-infant interaction'. *European Journal of Special Educational Needs*, 11 (1), 48-66.

Ofsted (1996/1997). *The Annual Report of Her Majesty's Chief Inspector for Schools: Standards and Quality in Education 1996/97*. London: The Stationery Office.

Ofsted (2000). Writing about Educational Inclusion: Guidance for Inspectors for Writing about Educational Inclusion in Inspection Reports. www.ofsted.gov.uk/publications.Open University Press.

Orange, J. B. & Purves, B. (1996). Conversational Discourse and Cognitive Impairment: Implications for Alzheimer's Disease. *Journal of Speech-Language Pathology and Audiology*. Vol 20, (2), p 139-150.

Orange, J. B., Ryan, E. B., Meredith, S. D. & McLean, M. J. (1995). Application of the communication enhancement model for long-term care residents with Alzheimer's Disease. *Topics in Language Disorders*, 15 (2), 20-25.

Orten, J. D, Allen, M. & Cook, J. (1989). Reminiscence groups with confused nursing centre residents: an experimental study. *Social Work Health Care,* 14, 73-86.

Phillipot, P., Feldman, R. S. & Coats, E. J. (Eds.) (1998). *The social context of nonverbal behaviour*. Cambridge: Cambridge University Press.

Parker, R. (1995). Reminiscence: A continuity Theory Framework. *The Gerontologist.* 35 (4), 515-525.

Paton, J., Johnston, K., Katona, C. & Livingston, G. (2004). What causes problems in Alzheimer's disease: attributions by caregivers. A qualitative study. *International Journal of Geriatric Psychiatry,* 19, 527-532.

Perkins, L., Whitworth, A., & Lesser, R. (1998). Conversing with the cognitively impaired. In M.Paradis (Ed.), *Pragmatics in neurogenic communication disorders* San Diego: Singular. Perkins, Whitworth & Lesser, 1998

Quackenbush, S. W. & Barnett, M. A. (1995). Correlates of reminiscence activity among elderly individuals. *International Journal of Aging and Human Development,* 41, 169-181.

Raia, P. (1999). Habilitation therapy: a new starscape. In *Enhancing the Quality of Life in Advanced Dementia.* Volicer, L. & Bloom-Charette-Charette, L. Eds. Taylor & Francis, USA, 1999, p. 21-37.

Ramanathan, V. (1995). Narrative wellformedness in Alzheimer discourse: An interactional examination across settings. *Journal of Pragmatics,* 23, 395-419.

Rau, M.T. (1993). *Coping with Communication Challenges in Alzheimer's Disease.* California: Singular Publishing Group Inc.

Richardson, A. P. & Marquardt, T. P. (1985). Language skills and communication breakdown in senile pAD. *Australian Journal of Human Communication Disorders,* 13, 75-93.

Ripich, D.N. (1994) Functional communication with AD patients: a caregiver training program. *Alzheimer Disease and Associated Disorders*, 8, 95-109.

Ripich, D.N., Vertes, D., Whitehouse, P., Fulton, S., & Ekelman, B. (1991). Turn-taking and speech act patterns in the discourse of senile dementia of the Alzheimer's type patients. Brain and Language, 40, 330-343.

Ripich, D.N., Ziol, E. & Lee, M.M. (1998). Longitudinal effects of communication of communication training on caregivers of persons with Alzheimer's disease. *Clinical Gerontologist,* 19 (2), 37-55.

Ripich, D.N., Ziol, E., Fritsch, T. & Durand, E.J. (1999). Training Alzheimer's disease caregivers for successful communication. *Clinical Gerontologist,* 21 (1), 37-56.

Ripich, D. N. (1994). Functional communication with AD patients: ca caregiver training program. *Alzheimer's Disease and Associated Disorders,* 8, 95-109.

Romaniuk, M., and Romanuik, J. (1981). Looking back: An analysis of reminiscence functions and triggers. *Experimental Aging Research,* 7, 477-489.

Rommetveit, R. (1974). *On message structure: A framework for the study of language and communication*. New York: Wiley.

Sabat, S.R. (2001). *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*. Blackwell.

Sabat, S.R. and Cagigas, X.E. (1997). Extralinguistic communication compensates for the loss of verbal fluency: A case study of Alzheimer's disease. *Language and Communication*, 17, 341-351.

Sabat, S.R., & Harre, R. (1992). The construction and deconstruction of self in Alzheimer's disease. In P.A. Mayhew, G.J. Acton, S. Yauk, & B.A. Hopkins (2001). Communication from individuals with advanced DAT: Can it provide clues to their sense of self-awareness and well-being? *Generic Nursing*, 22(2), 106-110.

Sacks, H., Schegloff, E.A.& Jefferson, G. (1974). A simple systematics for the organisation of turn-taking in conversation. *Language*. 50, 696-735.

Samuel, J. & Maggs, J. (1998). Introducing intensive Interaction for people with profound learning disabilities living in small staffed houses in the community. In D.Hewett, and M. Nind, (Eds.), *Interaction in action: reflections on the use of Intensive Interaction*. London: David Fulton: Publishers.

Schonnel, F.J. (1971) *Graded Word Reading Test.* Edinburgh: Oliver & Boyd.

Singh, S.; Bucks, R. S.; & Cuerden, J. M. (2001). Evaluation of an objective technique for analysing temporal speech variables in DAT spontaneous speech. *Aphasiology*, 15, 571-583.

Stokes, G. (2000). *Challenging Behaviour in Dementia. A Person-Centred Approach*. Speechmark Publishing Ltd: Oxon.

Stoppe, G., Brandt, C.A. & Staedt, J.H. (1999). Behavioural problems associated with dementia. The role of newer antipsychotics. *Drugs and Aging*. 14, 41-54

Stothard, V. (1998). 'The Gradual Development of Intensive Interaction in a School Setting', in D. Hewett. and M. Nind, (Eds.), *Interaction in Action: Reflections on the Use of Intensive Interaction*. London: David Fulton Publishers.

Sundin, K., Norberg, A. & Jansson, L. (2001). The meaning of skilled care providers' relationship with stroke and aphasia patients. *Qualitative Health Research,* 11 (3), 308-321.

Sweeting, H. & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness* 19, 93-117.

Tabourne, C. E. (1995). "The Effects of a Life Review Program on Disorientation, Social Interaction, and Self-Esteem of Nursing Home Residents," *International Journal of Aging and Human Development*, 41(3): 251-266.

Temple, V., Sabat, S.R., and Kroger, R. (1999). Intact use of politeness strategies in the discourse of Alzheimer's disease sufferers. Language and Communication, 19 (2), 163-180.

Terry, R. D. (2006). Alzheimer's disease and the aging brain. *Journal of Geriatric Psychiatry and Neurology*, 19 (3), 125-128.

Testa, J. A. (1999). Processing of emotional information by patients with Alzheimer's disease. *Dissertation Abstracts International Section B: the Sciences and Engineering*, May 1999, 59 (11-B0), 6112.

Todman, J. & Dugard, P. (2001). *Single-case and small-n experimental designs: A practical guide to randomization tests.* Mahwah, NJ: Lawrence Erlbaum Associates.

Tomasello, M. (1992). The social bases of language acquisition. *Social Development*, 1(1), 67-87.

Tomoeda, C. K. & Bayles, K. A. (1993). Longitudinal effects of Alzheimer's Disease on Discourse Production. *Alzheimer's Disease and Associated Disorders*, 7, 223-236.

Trevarthen, C. (2004). *Learning about ourselves, from children: Why a growing human brain needs interesting companions*. Retrieved September 16, 2005, from http://perception-in-action.ed.ac.uk/PDF_s/Colwyn2004.pdf.

Trevarthen, C. and Aitken, K.J. (2001). Infant intersubjectivity: Research, theory, and clinical applications. *Annual Research Review. The Journal of Child Psychology and Psychiatry and Allied Disciplines*, 42(1) 3-48.

Tronick, E.Z. & Weinberg, K.M. (1997). Depressed Mothers and Infants: Failure to Form Dyadic States of Consciousness. Murray, L. (Ed) & Cooper, P.J. (Ed). *Postpartum Depression and Child Development*.

Valenza, E., Simion, F., Macchi-Cassia, V., & Umiltà, C. (1996). Face preference at birth. *Journal of Experimental Psychology: Human Perception and Performance*, 22, 892–903.

Volicer L. & Bloom-Charette-Charette, L. (1999). Assessment of quality of life in advanced dementia. In *Enhancing the Quality of Life in Advanced Dementia*. Volicer, L. & Bloom-Charette-Charette, L. Eds. Taylor & Francis, USA, 1999, p. 3-17.

Vuorinen, E., Laine, M., & Rinne, J. (2000). Common pattern of language impairment in vascular dementia and in Alzheimer disease. *Alzheimer Disease and Associated Disorders*, 14, 81–86.

Vygotsky, L. S. (1962). *Thought and language*. (Hanfmann, E & Vakar, G, trans.). Cambridge, MA: MIT Press.

Watson, J & Fisher, A. (1997). Evaluating the effectiveness of Intensive Interaction teaching with pupils with profound and complex learning difficulties, *British Journal of Special Education*, 24, 80-87.

Woods, R. T. (1999) Psychological "therapies" in dementia. In R. T., Woods, (Ed.) *Psychological Problems of Ageing.* Chichester: Wiley.

Woods, R. T., Portnoy, S., Head, D., Jones, G. M. M. (1992). Reminiscence and life review with persons with dementia: which way forward? In G. M. M. Jones, B.M. L. Miesen (Eds.), *Care-giving in dementia: research and applications.* Tavistock/Routledge.

Woods, B., Keady, J. & Seddon, D. (2008) Involving Families in Care Homes: A relationship-centred approach to dementia care. London, Jessica Kingsley Publishers.

Zarit, S. H., & Edwards, A. B. (1999). Family caregiving: research and clinical intervention. In R. T. Woods, (Ed.). *Psychological Problems of Ageing.* Chichester: Wiley.

Zaudig, M.A. (2000). Risk benefit assessment of risperidone for the treatment of behavioural and psychological symptoms in dementia. *Drug Safety*. 23: 183-95.

APPENDIX I

Information sheets and consent forms

CIRCA PROJECT INFORMATION SHEET

Dementia poses some very serious challenges for those who develop it and for their family and carers. In particular, the loss of short-term memory which is characteristic of the disease makes communication very difficult for the person with dementia. Short-term memory helps to maintain the thread of a conversation, ensures that topics are fully discussed, and allows new topics to be introduced at appropriate times. When short-term memory is impaired, people with dementia may not appear to be following a conversation or may seem disinterested. This can be very disturbing and frustrating for all concerned. Therefore, finding ways to help with communication is vitally important.

The benefits of reminiscence and CIRCA's goals

Although short-term memory is impaired in dementia, long-term memory is often intact. Reminiscence sessions take advantage of this and allow the person with dementia to tell stories about their past and to enjoy the company of the person or people who reminiscence with them. Sessions are usually carried out by the use of a paper scrapbook. Music and videos that may spark memories of the past are also frequently used. Needless to say, this kind of reminiscence experience requires a lot of time and organization. The CIRCA project aims to alleviate these problems by producing an innovatively designed and easy to use reminiscence experience. It will be based on a computer, using multimedia techniques to incorporate music, video clips and pictures. The idea is to provide the person with dementia with a basis for their communication, giving a more lively and engaging form of reminiscence than is possible with a paper scrapbook. Early versions of the system have met with a great deal of interest from potential users, carers and professionals.

Where we need your help

For the multimedia reminiscence experience to have the best chance of success it will need to be easy and enjoyable to use, visually appealing and incorporate the best current practice in reminiscence. To cover all these aspects, a multidisciplinary team consisting of a software engineer, a designer, and a psychologist specializing in dementia will carry out the project. The Universities of both Dundee and St Andrews provide this expertise. Other collaborators include Alzheimer Scotland Action on Dementia and Dundee Social Work Department. To develop the most useful system, it is necessary that users and their carers test the reminiscence experience directly. This involvement will not only give the project team invaluable feedback but will also provide a positive and enjoyable experience for people with dementia and their carers.

Study 1 – Information sheet

Which types of generic photographs work best in reminiscence?

This information sheet introduces the CIRCA project. This three year research project is being run by the Universities of Dundee and St Andrews in collaboration with Dundee Social Work Department and Alzheimer Scotland. As you will read, the aim of the project is to provide a conversation aid for people with dementia and their carers via a multimedia reminiscence experience. The project is still in its very early stages and the team have planned a small preliminary study that will be conducted within residential and day-care units throughout the Dundee area.

This will firstly involve a short one-to-one question and answer session, known as the Mini-Mental State Examination. Following this, the person with dementia will be invited to look at a series of photographs of different annual events, for example, Christmas, Hogmany, Easter, etc. The aim of this research is to find out which pictures people with dementia take the most pleasure in and like to look at and/or talk about. This will provide vital information that will allow the team to move forward to the next step of the project. The session should last for between 10 and 15 minutes and is designed to be a pleasurable experience. However, the person with dementia can stop it at any time. The project team would like to videotape the sessions so that they can be assessed more accurately. The tapes will not be seen by anyone else and confidentiality will be maintained at all times. The person with dementia will also remain anonymous when the results of the research are written-up.

The CIRCA project team would therefore firstly like to ask for your consent to talk to the person you care for about the study. You will find a consent form that you are asked to sign and return should you agree. I am enclosing a postage paid envelope for your response. Please be assured that no approach will be made to the person you care for until we have received your reply. If you decide not to give consent, this will have no effect on the future care or treatment of the person you care for. Should you agree to this, the team psychologist will come to the unit to explain the study and to ask the person if he/she would like to take part. The session will then go ahead if the person is willing to do so.

The CIRCA team will also be holding a social event early next year that will further introduce the project to carers and people with dementia. This will provide more information on the project as a whole and will include an example of what the final multimedia reminiscence experience might look like. Invitations to this event will be sent out to you via ******** closer to the time.

If you have any queries about the current study or on the project as a whole, I can either pass on your comments to Maggie Ellis, the team psychologist or feel free to contact her on ***** ******.

Study 1 - Consent form

Which types of generic photographs work best in reminiscence?

I, the client's carer, consent to the client being approached to take part in this study.

Carer's name _____

Signature _____ Date _____

I consent to participate in this study.

Client's name _____

Signature _____ Date _____

I confirm that written consent has been obtained from the client.

Investigator's name _____

Signature _____ Date _____

Verbal consent

The client has been given this information and consent form. The study has been fully explained and the client has been asked to participate. The client was given the opportunity to ask questions about the study and it has been explained to the client that he/she is free to withdraw from the study at any time without his/her care being affected in any way.

Witness's name _____

Signature _____Date _____

Study 2 – Information sheet

How well do family photographs work in reminiscence?

This information sheet describes a study that is currently being run as part of the CIRCA project. This three year research project is being run by the Universities of Dundee and St Andrews in collaboration with Dundee Social Work Department and Alzheimer Scotland. As you will read, the aim of the project is to provide a conversation aid for people with dementia and their carers via a multimedia reminiscence experience. The project is still in its very early stages and the team have planned a second study that will be conducted within the residential homes of people with dementia and their caregivers throughout the Dundee area.

This will firstly involve a short one-to-one question and answer session, known as the Mini-Mental State Examination. Following this, caregivers and people with dementia will individually be invited to look at a series of their own family photographs. The aim of this research is to find out which pictures people with dementia and their carers take the most pleasure in and like to look at and/or talk about. This will provide vital information that will allow the team to move forward to the next step of the project. Firstly, you will be invited to reminisce in response to a selection of your own family photographs with the investigator. The session should last for between 10 and 15 minutes and is designed to be a pleasurable experience. However, you may stop it at any time. The session will then be repeated with your loved one with dementia. Again, he/she may stop the session at any point. The final session will involve both you and the person you care for reminiscing together in response to the photographs. The project team would like to videotape the sessions so that they can be assessed more accurately. The tapes will not be seen by anyone else and confidentiality will be maintained at all times. The person with dementia will also remain anonymous when the results of the research are written-up.

The CIRCA project team would therefore firstly like to ask for your consent to talk to the person you care for about the study. We would also like to ask for your own consent to take part. You will find a consent form that you are asked to sign and return should you agree. I am enclosing a postage paid envelope for your response. Please be assured that no approach will be made to you or the person you care for until we have received your reply. If you decide not to give consent, this will have no effect on the future care or treatment of you or the person you care for. Should you agree to this, the team psychologist will arrange a time to visit you at home to explain the study and to ask you and your loved-one the person if he/she would like to take part. The session will then go ahead if you are both willing to do so.

If you have any queries about the current study or on the project as a whole, I can either pass on your comments to Maggie Ellis, the team psychologist or feel free to contact her on ***** ******.

Study 2 - Consent form

How well do family photographs work in reminiscence?

I, the client's carer, consent to the client being approached to take part in this study. I also would like take part in this study.

Carer's name _____

Signature _____ Date _____

I consent to participate in this study.

Client's name _____

Signature _____ Date _____

I confirm that written consent has been obtained from the client.

Investigator's name _____

Signature _____ Date _____

Verbal consent

The client has been given this information and consent form. The study has been fully explained and the client has been asked to participate. The client was given the opportunity to ask questions about the study and it has been explained to the client that he/she is free to withdraw from the study at any time without his/her care being affected in any way.

Witness's name _____

Signature _____Date _____

Study 3 – Information sheet

Facilitating Communication in Severe Dementia

Communication problems in dementia

Dementia poses some very serious communication problems for those who develop it and for their family and carers. When a person has severe dementia, he or she may appear to be almost unreachable. Loss of speech and understanding can often make it seem as though the person is living in his/her own world. Therefore, finding ways to help with communication is vitally important.

The aim of this research

There has been very little exploration of ways of communicating with people with severe dementia. I wish to investigate several different methods as part of a programme of research. This research is at a very early stage and I am looking for people/a person to work with.

What would participation involve?

If you agree, I will visit the person you care for at ******** Care Home. All parts of this study will go ahead only if the person you care for wishes to do so. A member of staff at ******** will be present to witness this. If consent is given, I will visit the person you care for at ******** Care Home twice to start with. During these sessions I will ask him/her if we can have an informal talk. On consent, I will attempt to explore different approaches to communication and will videotape our interactions.

At several points during these interactions, I will adopt a position known as the 'Still Face'. This means that I will look straight ahead and make no attempt to interact with or respond to the person you care for. This procedure will be used to demonstrate the urge to communicate in the person you care for as I predict that he/she will indicate the wish to continue our interaction. This procedure will be interspersed throughout the interaction and will only be used for very short periods. The 'Still Face' will be stopped immediately should the person you care for show any signs of distress.

If the person you care for agrees, I will then visit him/her at ******** at five different times a day for five days with the purpose of trying out some further communication methods. This will serve as the main part of the study. The 'Still Face' will not be used in any of these interactions. This study is designed to be enjoyable and of benefit to the person you care for. However, he/she is free to withdraw from the study at any point.

I would like to film the person you care for in his/her environment at one point every day for the five days of the main study. The purpose of this is to look at what activities and interactions he/she would normally be engaged in. I will follow and film the person you care for for five minutes. I will film whatever he/she is doing at that point, excluding any activities of a personal nature. All sessions will be videotaped and will not be seen by anyone other than myself and my supervisor. However, should you wish to view the tape yourself, you

are welcome to do so. The identity of the person you care for will remain confidential at all times; including any reference to this study in my thesis. The videotapes will be kept in a locked drawer and will eventually be destroyed.

What happens now?
I would therefore firstly like to ask for your consent to talk to the person you care for about the study. A consent form is enclosed that you are asked to sign and return should you agree. Please be assured that no approach will be made to the person you care for unless your consent has been received. If either you or the person you care for decide not to give consent at any point during the study, this will have no effect on his/her future care. Finally, please note that I do not have access to your contact details and all correspondence with you has been conducted via ******** Care Home.

I welcome any questions you might have about this study. Please contact me at the University of Dundee on ******* ******** or at the University of St Andrews on ******* ******** if you would like to learn more about my research. I would be happy to send you a summary of my findings should the person you care for take part in this study.

Thank you,

Maggie Ellis
School of Psychology
University of St Andrews

Study 3 – Consent form

Facilitating communication in severe dementia

*I, the carer, consent to the person I care for being approached to take part in this research and to being videotaped.

Carer's name_____

Signature _____Date _____

Verbal consent
The researcher asked the person with dementia if he/she would like to have an informal talk. The person with dementia has agreed to this and to being videotaped and it has been explained that he/she is free to withdraw from the study at any time without his/her care being affected in any way.

Witness's name _____

Signature _____ Date _____

Researcher's name_____

Signature _____Date _____

****Contact Details:**

Name _____

Address_____

_____

Phone no. _____

* To be filled in by carer **Optional

Studies 4 & 5 – Information sheet

Developing the use of Intensive Interaction (II) as a means of communicating with people with very severe dementia

I invite you and the person you represent/care for to participate in a research project which may be of potential benefit to the person you represent/care for. However, before you decide whether or not you wish to participate I need to be sure that you understand firstly why I am doing it and secondly what it would involve if you agreed. I am therefore providing you with the following information. Read it carefully and be sure to ask any questions you have and if you want, discuss it with outsiders. I will do my best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

The background to the study

I am a researcher at the School of Psychology, University of St Andrews and I aim to conduct the following study as part of my PhD work. **'Developing Intensive Interaction for Advanced Dementia'** is a research project that I will carry out in care facilities throughout Tayside. In this month long project I aim to use a communication therapy known as Intensive Interaction with people at an advanced stage of dementia. Communicating using speech can become almost impossible at this stage of the illness and it is also extremely difficult for caregivers to understand what people with advanced dementia are trying to say. As such it is important that a non-verbal method of communicating is developed for these individuals and their caregivers. The person you represent/care for has been chosen as a possible participant in this research as he/she has been identified as being at an advanced stage of dementia and as such could benefit from the communication techniques that will be used in this research. Five other residents of other selected care homes will also be invited to participate.

Intensive Interaction is a therapy that was originally developed to aid communication for people with learning disabilities who also have extreme communication problems. It is based on the sounds and movements made by the person with learning disabilities which are copied and further developed by a healthy partner. These actions are then expanded by both people and are eventually built up into a non-verbal vocabulary. This technique could potentially benefit people with advanced dementia by providing them a method of communication that does not rely on speech.

What is involved?

The person you represent/care for may take part in the project by interacting with me. I would like to conduct six 10 minute long interaction sessions with each person over the course of 4 weeks. Three of these sessions will incorporate the techniques of Intensive Interaction and the other three will involve me attempting to involve the person in conversation. The 'conversation' sessions will be included in order to compare their success in encouraging communicative behaviours (such as increased eye contact, movements and sounds) to those produced during Intensive Interaction sessions. All sessions

will be videotaped to allow detailed analysis of these behaviours at a later date. This process will be as unobtrusive as possible and I will take the utmost care to make sure that the person is willing to continue at all times. If you agree to it, I will approach the person 5 minutes before I begin each interaction in order to check that he/she is not engaged in any other activity. At this point I will assess whether or not the person appears willing to engage with me by closely observing his/her verbal and non-verbal behaviours. A member of staff will also be present at this point to make sure the person is happy to proceed. Please be assured that you and the person you represent/care for may choose to participate or to stop participating at any point without giving a reason.

You will be issued with a timetable of the sessions that will take place between me and person you represent/care for. You will be invited to observe as many of the 6 interaction sessions you wish. You do not have to attend any of these sessions but if you do, travel expenses will be provided. If you decide not to attend any of the sessions I would be happy to arrange a meeting/home visit with you at your convenience to show you video recordings of them. Again, you will be under no obligation to view the tapes. Should you observe any of the sessions either in person or on videotape you will be invited to comment on what you have seen. If you agree, carers at the home can also take part in this study by commenting on videotaped interaction sessions. You also be invited to attend 4 weekly meetings with me, my supervisor and the manager of the home. The meetings will involve an update of the research and a discussion of how it is going. If you do not wish to or are unable to attend these meetings, I would be happy to contact you at home to discuss progress with you.

What are the discomforts, risks and side-effects?
Any instance of discomfort, risks or side-effects will be extremely unlikely in this study as the main aim is to help the participants to communicate. However, should you agree, I will organise a meeting with you and the key worker of the person you represent/care for to discuss what signs he/she might show of being unwilling to communicate with me. I would also like to visit the home before I start the study so that I can see what happens during a typical day and how the residents would normally act. This information will give me the best chance of recognising if any of the participants would be unwilling to take part or to stop the interaction. Should this occur the session will be stopped immediately.

What will happen to the information collected in the study?
The videotapes of the sessions will be stored in a locked drawer at the University of St Andrews and all participants will remain anonymous. Access to the tapes will be limited to me, my academic supervisor and one other researcher who will help me to analyse them. I will provide you with a summary of the results of the study and will be available to answer any questions you have about the research before and after it has been completed. I will write about the study in my PhD thesis and will submit a report of the findings to a psychology journal. Both of these publications will be available for you and others to read. Please be assured that neither you nor the person you represent/care for will be named in any write-up.

What happens now?
If you would like the person you represent/care for to take part please complete and return the accompanying consent form in the envelope provided. If you agree, I will contact you again when I have arranged the start date with the manager of the home. The form also has a section for you to fill in to let me know if you would like to take part yourself by viewing some sessions. The person you represent/care for may still take part if you do not wish to. I would also like to ask for your consent to inform the family doctor of the person you represent/care for about the study and his/her involvement in it. However, if you do not agree to this, the person you represent/care for may still take part. If you or the person you represent/care for decide not to take part, this will have no bearing on his/her future treatment at the home. Finally, please note that I do not have access to your personal details and all correspondence with you has been conducted via the home at this point. I welcome any questions you might have about this study. Please contact me on ***** ****** if you have any questions or would like to discuss this research further.

THANK YOU.

Maggie Ellis
School of Psychology
University of St Andrews

Phone:
01334 462017 (St Andrews)
01382 345119 (Dundee)

Studies 4 & 5- Consent form

Developing Intensive Interaction for Advanced Dementia

CONSENT FORM

NB. This form must be completed and signed by the guardian/welfare attorney/closest family member of the research participant in the presence of someone with knowledge of the research designated by the Principal Investigator. This may be a doctor, nurse, clinical research assistant or other member of the research team who must countersign the form as witness to the participant's signature.

Please circle your relationship to the research participant:

I am the guardian/welfare attorney/closest family member of the research participant.

If you circled 'closest family member', please state your familial relationship to the research

participant in the box below, i.e. wife, husband, son, daughter, etc.

I am the research participant's ☐

Please tick (✓) appropriate box

I am the closest living relative of the research participant.

Yes ☐ No ☐

The research participant has no welfare guardian.

Yes ☐ No ☐

Have you read and understood the Information Sheet? Yes ☐ No ☐

Have you been given an opportunity to ask questions and further discuss this study?

Yes ☐ No ☐

Have you received satisfactory answers to all of your questions?

Yes ☐ No ☐

Have you now received enough information about this study?
Yes ☐ No ☐

Who have you spoken to? Dr/Mr/Mrs/Miss……

Do you understand that participation is entirely voluntary? Yes ☐ No ☐

Do you understand that you and/or the person you represent/care for are free to withdraw from this study at any time?
Yes ☐ No ☐

Without having to give a reason for withdrawing? Yes ☐ No ☐

Without this affecting the present or future medical care of the person you represent/care for?
Yes ☐ No ☐

Do you agree to the person you represent/care for being approached to take part in this study?
Yes ☐ No ☐

Do you agree to being involved in the study by observing interaction sessions either in person or on videotape?
Yes ☐ No ☐

Representative's signature …… Date ……..

Participant's name in block capital letters ……

Telephone contact (Participant)…….(Home)

Signature witnessed by …….. Date…….

Witness name in block capital letters ……..…….

Studies 4 & 5 – Ethics letter

Ms Maggie P Ellis
Research assistant/Part-time PhD student
University of St Andrews
St Mary's College, South Street
St Andrews, Fife
Scotland
KY16 9JP

Dear Ms Ellis

Full title of study:	**Developing the use of Intensive Interaction (II) as a means of communicating with people with advanced dementia.**
REC reference number:	**06/MRE00/49**

The REC gave a favourable ethical opinion to this study on 25 May 2006.

Further notification(s) have been received from local site assessor(s) following site-specific assessment. On behalf of the Committee, I am pleased to confirm the extension of the favourable opinion to the new site(s). I attach an updated version of the site approval form, listing all sites with a favourable ethical opinion to conduct the research.

Research governance approval

The Chief Investigator or sponsor should inform the local Principal Investigator at each site of the favourable opinion by sending a copy of this letter and the attached form. The research should not commence at any NHS site until research governance approval from the relevant NHS care organisation has been confirmed.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/MRE00/49	**Please quote this number on all correspondence**

Yours sincerely

Kirstin Thompson

Miss Kirstin Thompson
Committee Co-ordinator

Email: kirstin.thompson@lhb.scot.nhs.uk

APPENDIX II

Cognitive Tests

COGNITIVE ASSESSMENT

Mini Mental State Examination:

Folstein, M. F., Folstein, S. E. & McHugh, P. R. (1975) Mini-mental state - a practical method for grading the cognitive state of patients for the clinician. *Journal of psychiatry*, 12, 189-198.

No. ..... Max points
Score
Date of birth.....
Date of test .....
Years of ed. .....

1.
a) Can you tell me today's (date)/(month)/(year)? ( ) ( ) ( )

.....

Which (day of the week) is it today? ( )

.....

Can you also tell me which (season) it is? ( ) **5** ( )

.....

b) What (city/town) are we in? ( )

.....

What (region) are we in? ( )

.....

What (country) are we in? ( )

.....

What (building) are we in? ( )

.....

What (floor) are we on? ( ) **5** ( )

.....

2.
*I'm going to say 3 words and I'd like you to repeat them after me
(ball, car, man) ( ) **3** ( )
(repeat up to 6 trials until all words are remembered)
(trials:)

3.
a) Think of the number 100. Can you tell me what 100 take away 7 is?
Repeat and stop after 5 answers. (93__86__79__72__65__).

.....

AND

b) Can you spell 'WORLD' backwards? (D_L_R_O_W_) **5** ( )

.....

4.
Do you remember what the 3 words were I said earlier? **3** ( )
**Skip this according to 2.*

.....

5. What do you think this is? (Show a watch) (show a pencil) **2** ( )

.....

6. Repeat after me: "no ifs, ands or buts" **1** ( )

.....

6. *Show 'CLOSE YOUR EYES'* (see sheet)
Can you read this sentence and then do what it says? **1** ( )

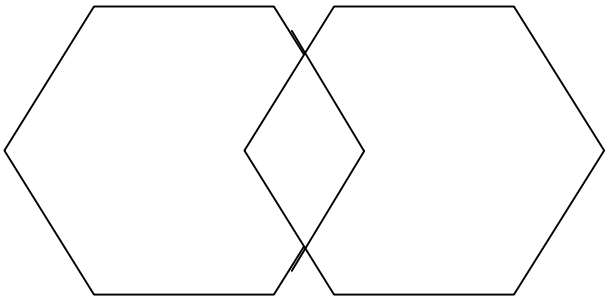
.....

Can you write a short sentence for me please? (see sheet) **1** ( )

.....

7. *Present paper*
Put this paper in your hand
Fold it in half
And put it on the floor **3** ( )

8. Will you copy this drawing please? (see sheet) **1** ( )



6.

CLOSE YOUR EYES

Schonnel Graded Word Test (SGWT):

Schonnel, F.J. (1971) *Graded Word Reading Test.* Edinburgh: Oliver & Boyd.

Tree	Crowd	Physics	Oblivion
Little	Sandwich	Campaign	Scintillate
Milk	Beginning	Choir	Satirical
Egg	Postage	Intercede	Sabre
Book	Island	Fascinate	Beguile
School	Saucer	Forfeit	Terrestrial
Sit	Angel	Siege	Belligerent
Frog	Ceiling	Recent	Adamant
Playing	Appeared	Plausible	Sepulchre
Bun	Gnome	Prophecy	Statistics
Flower	Canary	Colonel	Miscellaneous
Road	Attractive	Soloist	Procrastinate
Clock	Imagine	Systematic	Tyrannical
Train	Nephew	Slovenly	Evangelical
Light	Gradually	Classification	Grotesque
Picture	Smoulder	Genuine	Ineradicable
Think	Applaud	Institution	Judicature
Summer	Disposal	Pivot	Preferential
People	Nourished	Conscience	Homonym
Something	Diseased	Heroic	Fictitious
Dream	University	Pneumonia	Rescind
Downstairs	Orchestra	Preliminary	Metamorphosis
Biscuit	Knowledge	Antique	Somnambulist
Shepherd	Audience	Susceptible	Bibliography
Thirsty	Situated	Enigma	Idiosyncrasy

APPENDIX III

Example of photographic stimuli

STIMULI

PHOTOGRAPHS

Example of photographs depicting Christmas using images of people, scenes and food in both black and white and colour formats.






APPENDIX IV

Transcript examples

EXAMPLES FROM TRANSCRIPTS

Mild Stage

Sex: Male

MMSE: 24

This person tended to use the photograph as either something to interpret or as a platform to describe detail from the participant's own life. The flow of conversation appears to be quite natural and appropriate but with some instances of empty phrases.

Investigator: *"Here's a picture of people at Easter. What are your memories of Easter?"*

Person with dementia: "Religion."

I: *"Hmmm?"*

P: "Family. Er, I think being sick with the amount we used to eat."

I: *"(Laughs) I think we've all got that memory (laughs)."*

P: "I know. Er, I can't say anything about the girl because I was on my own when I was a youngster and there's no girls in my family. Well, my family, my own family, I've got. I'm the eldest of four brothers, you see."

I: *"Hmmm."*

P: "Er, what can I see in these two kids? Satisfaction."

I: *"Hmmm."*

P: "Friendship. Probably family friendship."

I: *"Hmmm."*

P: "Uh-huh. It means that what they've got in their hands are the only two eggs available. Oh no it's not. There's another. There's another two there, yeah.

What else was there there? Bowls of confectionary of some description. Satisfaction."

I: *"Hmmm?"*

P: "Happiness."

I.: *"Yeah. Does it remind you of any Easters that you spent around that age? What you used to do."*

P: "Not really. The thing about my early life was that ah, I was born 1917 which was of course was er, part of the great world war, *y*ou know?"

I: *"Hmmm?"*

P: "And my mother, who *had* to work, dumped me off with my grandmother."

I: *"Hmmm?"*

P: "Her mother. And er, it wasn't 'til after the war that we sort of got together, you know? And er, I thought oh yeah. That's my mother, you know?"

I: *"Hmmm."*

P: "Isn't it funny? Do I see anything else? There's a bird there of some er, I don't know why it's bird with eggs and er."

I: *"Hmmm?"*

P: "I don't see any meaning in that. It's Easter, of course but er, I think that's all I see in it."

Moderate stage

Sex: Female

MMSE: 15

This person tended to describe the contents of the photograph rather than attempting to interpret what was happening in it. Instances of inappropriate laughter where there was no obviously humourous preceding comment were clear in this person's discourse. This person's discourse was rather more general in nature and dependant on stock phrases and empty phrases.

M.P.E.: Here's a picture of food that you might have at Easter.

Participant: Aye (laughs)

M.P.E.: What are your memories of Easter?

Participant: Oh, the chicken.

M.P.E.: Hmmm?

Participant: (long pause) Eggs.

M.P.E.: Hmmm?

Participant: (inaudible)

M.P.E.: Hmmm?

Participant: When can we get a taste of it?

M.P.E.: (laughs)

Participant: That's all I can think about.

M.P.E.: Pretty soon, I think. It's coming close to that time of year (both laugh). Does it bring back any memories of Easter to you? Easters that you might have had when you were younger or…

Participant: No, I wouldn't say, we had Easter eggs.

M.P.E.: Hmmm?

Participant: You know?

Advanced stage

Sex: Female
MMSE: 10

This person was very unsure of the situation and what was being asked of her. This participant was quick to mention her memory problems and made no attempt to mask them.

M.P.E.: Here's a picture of food that you might eat at Easter. What are your memories of Easter?

Participant: I can’t bring it to mind.

M.P.E.: OK, we'll just move on.

Participant: No, I can't bring it to mind.

M.P.E.: That's alright, that's OK. We'll just carry on.

APPENDIX V

Coding Booklet – Study 1

STUDY 1

CODING BOOKLET

SAMPLE TRANSCRIPT

1. Christmas/scene/colour – gp

ME: Christmas

1. AMc: Yes

ME: Anything else? Does it make you remember anything specifically, or

2. AMc: Well, everybody thinks San for Santa Claus coming, isn't it?

ME: Hmmm

3. AMc: And all the decorations are lovely, aren't they? Yes, uh-huh.

4. Yeah, that's about all. I like all the decorations on the tree. They're

5. very nice.

ME: Does it remind you of any Christmases you had?

6. Participant: Well the tree, not as big a tree as that. Certainly not. But, er,

7. with the decorations and that on the tree. You know, it's always nice

8. to look back on, isn't it? Uh-huh. So that would be about it I suppose

9. (laughs).

ME: OK

10. AMc: It was a tree but not as big as that (laughs).

ME: Right, OK.

2. Easter/people/b&w - sp

ME: Here's a picture of people at Easter.

11. AMc: Uh-huh

ME: What are your memories of Easter?

12. AMc: Well, with it rolling your egg actually. That's what I used to do

13. roll my egg on Easter.

ME: Hmm?

14. AMc: Er. And this is the chicken isn't it, here?

ME: Yeah

15. AMc: Yes. And all Easter. They're all Easter eggs there, aren't they?

ME: Yes

16. AMc: Uh-huh..er, oh that's a, a, is that a creme egg. Oh that's a

17. creme egg, that one. And the paper there. Yes, er, (2) they're

18. certainly eating them anyway (both laugh).

ME: Yeah, there's no doubt about that.

19. AMc: No, that's right, uh-huh. Now do you think that's about it I can

20. tell you about?

ME: Hmm. Does it remind you of any Easter times that you spent?

21. AMc: Yeah well, at home. Never, never with plates with so many

22. eggs in them because there was only me (laughs). Any my mother

23. and father, you know? But er, yes. Just something just similar like

24. that, you know? It was alright.

ME: Hmm

25. AMc: Yes they were in a put in a not, not a big a plate as that

26. because there was only three eggs, that was all. My mother and

27. father and myself (laughs). So that was about it. And no, there was

28. no chicken that I can remember about. But er, that was the, the eggs

29. were there.

ME: Hmm

30. AMc: That's about it I think. Yes, uh-huh. That's it.

ME: OK

<u>3. New year/food/colour - gp</u>

ME: What memories come to mind

31. AMc: New year

ME: OK

32. AMc: Yes, uh-huh. Cake and shortbread. Yes that's what you used

33. to get your new year when you went into anybody's, anybody's

34. house. Mmm, you got that for your new year (laughs). And a drink

35. of maybe, well you were too young for wine, but a drink of lemonade

36. (both laugh). So that was that (laughs).

ME: Uh-huh

37. AMc: And that was my new year.

Me: Uh-huh

38. AMc: Until I got older and then I got wine (laughs).

ME: That's better

39. AMc: Yeah and that was after I left school, of course.

ME: Uh-huh

40. AMc: (laughs) Not before (laughs). But that was that. We used to

41. have some good times at new year.

ME: Hmm

42. AMc: Yes. It's a happy time, isn't it?

ME: Yeah

43. AMc: Yes, uh-huh. I liked that, so that's that.

ME: OK

44. AMc: Hmm

4. Holidays/scene/b&w - sp

ME: Here's a picture of a holiday scene.

45. AMc: Yes, uh-huh.

ME: What are you memories of

46. AMc: Oh, passport. Well, that's if you're going on a plane or

47. whatever. You need a passport, don't you, really? Yes, er, och I just

48. used to go, er actually we went er Blackpool one year.

ME: Hmmm

49. AMc: But more or less it was just to an aunt we had that lived in the

50. country. And that's when we used to, seven weeks holidays. It used

51. to be great going there. That's how I spent my holidays.

ME: Uh-huh

52. AMc: Going to my aunt's (laughs). It was very good (laughs).

53. Changed days now (laughs).

ME: Yeah

54. AMc: Uh-huh. So that was that and of course, you need your

55. passport if you're going abroad.

ME: Hmmm

56. Amc: Yes, uh-huh. But I was never abroad. Not that far anyway

57. (both laugh). Maybe one day.

ME: Oh yeah, you never know.

58. AMc: No, you never know your luck (both laugh). So is that

59. everything?

ME: OK?

60. AMc: Uh-huh

ME: Got a couple more here 'A'.

61. AMc: Yeah, right.

5. Burns night/people/colour - gp

ME: What memories come to mind when you look at that picture?

62. AMc: Oh, that, oh, dear. There's a friend of the family. He plays the

63. pipes.

ME: Hmmm

64. AMc: And we have lots of good fun when he comes to the house,

65. you know, and brings the pipes with him. And we're all in the middle

66. of the floor having a bit of a dance and that so it's very good actually.

ME: Uh-huh

67. AMc: Makes your day.

ME: Yeah

68. AMc: (laughs) Happy times, yes. Oh yes. I don't know their names at

69. all, no.

ME: I think that's Burns night

70. AMc: But oh, is that what that, oh, yes. Is that a haggis?

ME: Hmmm

71. AMc: Yes, that'll be what that is. Haggis, oh I don't I've never seen

72. haggis. That'll be it I suppose. Haggis is it?

ME: Hmmm

73. AMc: Yes, uh-huh. Oh, it's the first time I've seen it. I've heard about

74. it but I've never seen it (both laugh). That's a nice photograph, isn't

75. it?

ME: Yes, it is.

76. AMc: Uh-huh, yes. Got his pipes with him too.

ME: Hmmm

77. AMc: Bring in the new year (laughs). Very good. (1) Yes

ME: OK?

78. AMc: Uh-huh

6. Birthday/food/b&w - sp

ME: Here's a picture of food that you might have on someone's birthday.

79. AMc: Oh birthday, birthday cake. Yes, I've had one of those once

80. upon a time. Yes, uh-huh. They're lovely, aren't they?

ME: Yes, they are.

81. AMc: Very nice. Oh yes, uh-huh. Happy birthday. 'A', they used

82. to put at the bottom of mine (both laugh). Very good.

ME: Uh-huh

83. AMc: Yes, happy times (1). Yes, I was twelve when I had my birthday

84. party.

ME: Uh-huh

85. AMc: Yes, and you never forget those kind of things. It was once in

86. a blue moon when you got a birthday party. Well I, once in a blue

87. moon for me and it was my twelfth birthday. That's why I've never

88. forgotten it (both laugh). And I had a cake and that too.

ME: Uh-huh

89. AMc: Yes, it was very good. Thoroughly enjoyed it. And all our

90. chums were there and had a great time.

ME: Good

91. AMc: (laughs) Brings back memories (both laugh). Long time ago.

ME: Uh-huh

92. AMc: So, that was that.

ME: OK 'A'

93. AMc: Thank you, yes, uh-huh.

NOTES:

CODING CATEGORIES AND OPERATIONAL DEFINITIONS

CONTINUATION ELEMENT	OPERATIONAL DEFINITION	EXAMPLE
1. Turn- taking	Amount of *all* types of turns in response to photographs	Minimal turns Single or multiple utterances Story-telling Stock expressions, etc, etc.
Further information: Turns can be very long (as in story telling) or very short (as in minimal turns). Turns end when the conversation partner contributes to the interaction.		
2. Use of minimal turns	Single word turns – can be a filler, i.e. "So"	"Mhhm" "Ah" "Yeah" "Right"
Further information: Don't code as filler if the word serves as an entire turn.		
3. Utterances	Any sentence whether related or unrelated to the topic. Any statement separated by a *full stop.*	"I used to go camping in Fife when I was little." "I went with my friends." "We used to play football."
Further information: Code utterances from the line they *start* on.		
4. Story-telling	Any combination of three or more utterances that *narrates* a general or specific single or recurring situation or event from the person's own experience. Either seemingly related *or* unrelated to the stimulus topic.	"I used to go camping in Fife when I was little. I went with my friends. We used to play football."
Further information: Remains a story even if the narrative is broken by a turn by the conversation partner or is interspersed with comments on another topic (see lines 79-90 on practice script). Remains a story if the PWD returns to the same topic however, this must occur in response to the *same* picture.		
5. Unrelated recurring theme	Subject introduced and reintroduced after a **new** topic has been initiated whether by the PWD or the conversation partner.	"My father was killed in the first world war". "My father was shot during the first world war".
Further information: Must occur in more than one picture to make sure that it		

is an unrelated occurring theme. State what each theme is and how many times the PWD returns to it.		
6. Maintaining partner's involvement	Questions that do not require the provision of new information of the conversation partner.	"That's nice, isn't it?" "Santa Claus is coming, isn't he?"
Further information: Almost a rhetorical question. Expects and requires only a minimal turn from the conversation partner. Used to check that the conversation partner is engaged.		

7. Requests for information	Any question that requires any type of further information from the conversation partner.	"Can you repeat that, please?" "Pardon?" "Sorry?" "Where?" "When? "Where did you go to school?"
Further information: The PWD passes the floor to the conversation partner. Requires the partner to make a bigger contribution to the conversation than 6.		
8. Modulations	Any comment made by the PWD about her performance during the task	"Am I doing OK?" "Am I making a right mess of this?" "I'm enjoying this."
Further information: These often take the form of questions but don't code as 6 or 7 if it is concerned with any aspect of the task itself.		

FACE-SAVING ELEMENT	**OPERATIONAL DEFINITION**	**EXAMPLE**
1. Fillers	A *single* sound or word which does not give meaning to the utterance.	"Oh." "Well." "Uh." "Actually." "Mmm." "Hmm." "Anyway."
Further information: Can be a combination of fillers – i.e. "so, anyway" would counts as 2 fillers.		
2. Imitation	Any utterance that repeats one or more elements of what has just been said by the experimenter	E: "What are your memories of Christmas?" PWD: "Memories of Christmas?
Further information:		

Either a single word or a phrase. Don't include if the word repeated by the PWD can be read on the photograph, (i.e. line 79 on the practice script). If the person repeats the word used by the conversation partner in this case, code it as a descriptor.		
3. Descriptor	Any comment that refers to either all or a single detail of items in the photograph or the photograph itself either directly or indirectly: including *reading*: and *counting* from the photo:	Direct: "That's a nice *Christmas tree*." "That's a nice photograph." Indirect: (When looking at a glass of whisky) "I would like that glass of lemonade." "That says *Keith* and *Lorraine*." "There's *1, 2, 3, 4, 5 candles* there."
Further information: Count each time even if repeated, i.e. "That's a nice *tree*." … "That *tree* is lovely." This represents each time the PWD uses the photograph as a conversational prompt. Don't code single elements, ie. "tree", "decorations". Code as phrases.		

NOTES:

4. Stock expressions	An expression used more than three times in response to stimuli that does not add meaning to the utterance.	"There you go." "You know." "Goodness." "So that was that." "Yes, uh-huh."
Further information: State what each stock expression is and note how many times the PWD uses it. There can be slight variations in the wording, i.e. "So that's that." "So that's it." "So that's about all."		
5. Topic change	Any instance within which the person abruptly changes the subject of conversation	E:" What are your memories of Christmas?" PWD: "What's that outside the window?"
Further information: Don't code if an unrelated recurring theme.		
6. Inappropriate laughter	Any instance of laughter that is not in response to obvious use of humour.	E: "What are your memories of Christmas?" PWD: "Oh well, I couldn't say (laughs)!"
Further information:		

Code as inappropriate even if both partners laugh.		
7. Singing/Reciting	Any instance of singing or reciting verse	"Wee sleekit cowerin' timorous beastie."
Further information: Code each time the PWD engages in this during the transcript.		

Name: **Script Number:**

CONTINUATION ELEMENTS

	Turn-taking
Total =	**Picture1: 1 = 2 = 3 = 4 = 5 = 6 =:** **Total per picture: 1 = 2 = 3 = 4 = 5 = 6 =** **Total:**

LINE NUMBER

1. Use of minimal turns	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6
2. Utterances	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6
3. Story-telling	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6

NOTES:

4. Maintaining partner's involvement	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6
5. Requests for information	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6
6. Modulations	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6

7. Recurring unrelated theme	Theme:				
	Pic1 Total:	Pic 2 Total:	Pic 3 Total:	Pic 4 Total:	Pic 5 Total:	Pic 6 Total:
	Theme:				
	Pic1 Total:	Pic 2 Total:	Pic 3 Total:	Pic 4 Total:	Pic 5 Total:	Pic 6 Total:
	Theme:				
	Pic1 Total:	Pic 2 Total:	Pic 3 Total:	Pic 4 Total:	Pic 5 Total:	Pic 6 Total:
	Theme:				
	Pic1 Total:	Pic 2 Total:	Pic 3 Total:	Pic 4 Total:	Pic 5 Total:	Pic 6 Total:

FACE-SAVING ELEMENTS

LINE NUMBER

1. Stock expressions	Expression:					
	Pic1 Total:	Pic 2 Total:	Pic 3 Total:	Pic 4 Total:	Pic 5 Total:	Pic 6 Total:
	Expression:					
	Pic1 Total:	Pic 2 Total:	Pic 3 Total:	Pic 4 Total:	Pic 5 Total:	Pic 6 Total:
	Expression:					
	Pic1 Total:	Pic 2 Total:	Pic 3 Total:	Pic 4 Total:	Pic 5 Total:	Pic 6 Total:
	Expression:					
	Pic1 Total:	Pic 2 Total:	Pic 3 Total:	Pic 4 Total:	Pic 5 Total:	Pic 6 Total:

2. Fillers	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6
3. Imitation	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6
4. Descriptors	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6
5. Topic change	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6

NOTES:

6. Inappropriate laughter	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6
7. Singing/reciting	Picture 1	Picture 2	Picture 3	Picture 4	Picture 5	Picture 6

NOTES:

Glossary

A'richt	Alright
Auld	Old
Auld besom	Old grouch
Bide	To live with
Bitties	Bits
Braw	Good
Cannae	Can't
Dinnae	Don't
Dro	Reading aloud from picture
Och aye	Oh yes
Smit	Infect/pass on to
Ta'en	Taken
The sosh	The co-op
The wee ane's	The little ones
Wee sleekit cowerin' timorous beastie	Quote from Burns' poetry
Whence	Where/from what place?
Whinds	Place name
Ye ken/ken	You know

APPENDIX VI

Questions – Study 4

- Hello ****, I'm Maggie. Would you like to have a chat with me?
- Are you well today?
- Have you had breakfast/lunch/dinner?
- Did you enjoy your meal?
- Have you had a good day so far?
- Did you sleep well last night?
- Did you go to bed early?
- Did you have a lie in this morning?
- Have you taken part in any activities today?
- Do you usually take part in the activities?
- Do you enjoy the activities here?
- Have you seen the news today?
- Did you see the weather report?
- Have you seen the weather outside today?
- It's lovely/miserable, isn't it?
- It's looking more like spring/summer/autumn/winter now, isn't it?
- It'll soon be spring/summer/autumn/winter won't it?
- Are you looking forward to it?
- Well, thanks for your time. It was nice talking to you.
- I have to go now. I'll see you again soon. Bye.